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Functional recovery: A mixed methods study of the specific variables within a post-hospital inter-disciplinary brain injury rehabilitation - residential program

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Functional Recovery: A Mixed Methods Study of the Specific Variables within a Post-Hospital Inter-
Disciplinary Brain Injury Rehabilitation - Residential Program

Victoria Harding

A proposal submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

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Dedication

I dedicate this dissertation to individuals and their families who are recovering from brain injury. Their perseverance gives purpose to every day.

Acknowledgements

It is a great pleasure to acknowledge and thank everyone who helped me on my journey that is this dissertation. I am truly eternally indebted to my advisor, Dr. Cynthia O'Donoghue, who worked tirelessly to help me at every corner and crossroads of this research and who has provided invaluable guidance and support throughout this project.

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Abstract

The mixed methods explanatory design study examined specific constructs of Post Hospital Interdisciplinary Brain Injury Rehabilitation – Residential (PHIDBIR-R) programs that positively influenced gains in function. The investigation involved exploring the phenomenon of individuals' experiences while participating in a PHIDBIR-R program as part of recovery from brain injury. The study's primary purpose was to understand individuals who make the greatest gains in function while participating in these programs, as measured by the Mayo-Portland Adaptability Inventory-4 (MPAI-4) change scores from admission to discharge and what are the components of these programs that may contribute to individuals' gains in function.

Data were collected via repeated measurement of the MPAI-4 to determine top performers and characteristics of those performers, and to understand which components of the MPAI-4's 29 areas of measurement most contributed to their change scores. Next, semi-structured interviews with 10 of the top performers was completed. Inclusion criteria included: sustained a traumatic brain injury; aged 18 or older; be identified as one of the top performers; agree to participate. Numerous procedures enhanced trustworthiness, including peer reviewers, member checking, and memo-writing.

Data were analyzed using constant comparison procedures. Thirteen themes within four major categories were reflected in the data. Themes reflect participants' understanding of crisis, crisis counseling, crisis supervision, and clinical supervision. The results provided a cogent framework for PHIDBIR-R program development, stakeholder program selection and advocate and legislator consideration for program inclusion for optimal outcome. Contributions to the literature and future research recommendations are also explored.

CHAPTER I

Introduction and Overview of the Study

Introduction

Stories involving brain injury permeate social media and the news: a football player is injured in a tackle, an exposure to a blast disables a soldier, a teen is hurt in a motor vehicle crash, a politician becomes victim of a gunshot to the head, an older adult falls, a child experiences a near drowning, a country music star suffers a stroke, a stockbroker is mugged, an electrician falls off a ladder. The list is long and examples, plentiful. In a matter of seconds, a person's concerns about tomorrow change from everyday household and life activities (e.g., paying the bills, getting the kids to school on time, picking up groceries, going on a big date, getting promoted, mowing the lawn, or finishing a paper) to suddenly struggling to survive a brain injury.

Learning the potential consequences of brain injuries can be alarming. Often, there are associated impairments in functioning that affect multiple aspects of the individual's daily life. The formidable fact about the circumstances and mechanisms by which brain injuries are sustained is that brain injury does not discriminate: a brain injury can happen to any person, at any time. Furthermore, the injury does not only affect the individual who has sustained the brain insult. Anxious and grief-stricken families witness their loved one's coma, intensive care, sophisticated medical procedures, medications, and a new reality in which survival is the daily goal. Once it is clear that the individual will survive the immediate aftermath of a brain injury and medical conditions have stabilized, new goals emerge - the regaining of lost function. This represents rehabilitation after brain injury.

A variety of terms are used to describe changes in neuronal activity within the brain. Labels frequently utilized have become specific and reflective of different causes and resulting effects to the physical integrity, the metabolic activity, or the functional ability of brain cells. However, when considering the general term *brain injury*, most are in agreement that this refers to injury to the brain that results in mild, moderate, or severe impairments in one or more areas: cognition, speech-language communication, memory, attention and concentration, reasoning, abstract thinking, physical functions,

psychosocial behavior, and information processing (Brain Injury Association of America [BIAA], 2012; Brain Injury Alliance of New Jersey, 2012).

Causes of brain injury can include, but are certainly not limited to: airway obstruction, near-drowning, throat swelling, choking, strangulation, crush injuries to the chest, electrical shock or lightning strike, trauma to the head or neck, traumatic brain injury with or without skull fracture, blood loss from open wounds, artery impingement from forceful impact, shock, vascular disruption, heart attack, stroke, arteriovenous malformation, aneurysm, intracranial surgery, infectious disease, intracranial tumors, metabolic disorders, meningitis, certain autoimmune deficiency and venereal diseases, insect-carried diseases, brain tumors, hypo/hyperglycemia, hepatic encephalopathy, uremic encephalopathy, seizure disorders, and toxic exposure to poisonous chemicals and gases such as carbon monoxide poisoning (Zasler, Katz, & Zafonte, 2007).

Just as each individual is unique, so is each individual's brain and experience of brain injury. Many families affected by brain injury initially observe that physical disabilities, impaired learning, and personality changes are common. Frequently reported problems in functioning include changes in speech and hearing, paralysis, management of pain, headache, changes in vision, seizure disorders, muscle spasticity, reduced endurance, cognitive impairments affecting concentration, attention, perceptions, ability to plan, receptive communication, writing skills, short-term memory, long-term memory, judgment, sequencing of activities, reading skills, and orientation. Behavioral and emotional changes may be evidenced in fatigue, anxiety, low self-esteem, restlessness, agitation, rapid changes in mood, excessive emotions, depression, sexual dysfunction, lack of motivation, inability to cope, self-centeredness, and aggression (Karol, 2003).

Acquired brain injury (ABI) is an injury to the brain that occurs after birth; one that is not hereditary, congenital, degenerative, or induced by birth trauma (BIAA, 2012). Acquired brain injury occurs at the cellular level within the brain. Therefore, injury resulting from acquired brain injury can affect cells throughout the entire brain, in contrast to injury in only specific areas of the brain experienced with traumatic brain injury. A traumatic brain injury (TBI) is subtype of a more general ABI. TBI is

defined as an alteration in brain function or other evidence of brain pathology caused by an external force (BIAA, 2012). Thus, a TBI is a specific type of acquired brain injury. Traumatic brain injuries (TBIs) are considered the most common type of brain injury reported in the media. Other types of brain injury may include stroke, brain tumor, aneurysm, viral encephalitis, anoxic brain injury, or progressive neurologic disorders such as Multiple Sclerosis (BIAA, 2012).

The pervasiveness of TBI is well documented. Every year in the United States at least 1.7 million TBIs occur either as an isolated injury or accompanied by other injuries or illnesses. At least three TBIs occur each minute. TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States (Faul, Xu, Wald, & Coronado, 2010). In the United States, 5.3 million people live with TBI-related disability (Thurman, Alverson, Dunn, Guerrero, & Snieszek, 1999).

TBIs cost Americans \$76.5 billion in medical care, rehabilitation, and loss of work every year (Finkelstein, Corso, & Miller, 2006; Coronado, McGuire, Faul, Sugarman, & Pearson, in press). The annual incidents and cost of other forms of brain injury raise these numbers even higher. The estimated annual incidence of stroke in the United States, for example, is 795,000 (Centers for Disease Control and Prevention [CDC], 2009) with an estimated economic cost of \$5.9 billion in 2010 (Roger, Go, & Loyd-Jones, 2010). Further, the estimated annual number of brain tumors in the United States is 64,530 along with 27,000 aneurysms, 20,000 viral encephalitis cases, and 10,400 with Multiple Sclerosis (Central Brain Tumor Registry of the United States [CBTRUS], 2012; CDC, 2005; CDC, 2009; National Heart Blood and Lung Institute, 2011). No national data are available for anoxic brain injury and other subtypes of brain injury (BIAA, 2012).

When all types are considered together, the annual occurrence of a brain injury incident in the United States is close to 8.5 million. Improvements in medical care and health have resulted in an increase in life expectancy with a resultant steady increase in the number of older adults living with a brain injury (Cifu, 1993; Cifu, Means, Cunie, & Gershkoff, 1993). As evidenced in the data presented above, brain injury has affected many people in the last decade and lifelong challenges post-injury are likely to continue to affect those seeking recovery.

How are Brain Injuries Studied?

In April of 2013, President Obama announced the new research effort, Brain Research through Advancing Innovative Neurotechnologies (BRAIN), which is aimed at revolutionizing our understanding of the brain and uncovering new ways to treat, prevent, and cure brain disorders like Alzheimer's, schizophrenia, autism, epilepsy, and traumatic brain injury (The White House, 2013). The Department of Veterans Affairs and the Department of Defense announced on September 19, 2012 that they are jointly investing more than \$100 million in research to improve diagnosis and treatment of mild TBI and Post-traumatic Stress Disorder (Department of Defense [DOD], 2012). Commitment to funding our understanding of brain injury continues as a focus at the national level.

It is beyond the scope of the current research to provide discussion about the research focus, methods, and clinical research trials currently underway to better understand brain injury or the biological mechanisms underlying damage to the brain. Also not discussed are studies, strategies, or interventions attempting to alter the cellular changes caused by brain injury by applying specific proteins or medications, surgical interventions, temperature or oxygen level changes, devices, or that attempt to limit primary and secondary brain damage occurring within days of a head trauma event. The focus of the current research is squarely within the area of rehabilitation following traumatic brain injury, mainly, the therapies implemented to both treat brain injury and assist in the long-term recovery of function.

Rehabilitation represents one piece of the recovery process for an individual who has suffered a brain injury. During the acute hospitalization phase of recovery, individuals who have sustained moderate to severe brain injuries may receive treatment and care in an intensive care unit of a hospital. Once medically stable, the individual may be transferred to a sub-acute unit of the medical center, or, to an independent rehabilitation hospital. At this point, individuals follow many diverse paths toward recovery because there are a wide variety of options for rehabilitation (National Institute for Neurological Disorders and Stroke, 2013).

In 1998, the National Institutes of Health (NIH) held a Consensus Development Conference on Rehabilitation of Persons with Traumatic Brain Injury. The Consensus Development Panel recommended

that TBI patients receive an individualized rehabilitation program based on the unique patient's strengths and capacities, and that rehabilitation services should be modified over time to adapt to the patient's changing needs (NIH, 1999). The panel also recommended that persons with moderate to severe brain injuries receive rehabilitation treatment that draws on the skills of many specialists. This involves individually tailored treatment programs in the areas of physical therapy, occupational therapy, speech-language therapy, physical medicine, psychology and psychiatry, and social support. Additional medical personnel providing care include rehabilitation nurses and a team coordinator or administrator (National Institute for Neurological Disorders and Stroke, 2013).

As the literature review in the following chapter details, research of rehabilitation following brain injury has focused on either evaluation of one specific treatment modality, typically in contrast to another specific treatment or modality, or evaluation of a program's or environment of care's efficacy as measured by a variety of outcomes measurements. Research has sought to determine *if* rehabilitation has been successful, perhaps to the detriment of learning *how* rehabilitation has been successful for those individuals who have made measureable gains.

How Is Rehabilitation Provided for Individuals with Brain Injury?

The overall goal of rehabilitation after brain injury is to improve an individual's ability to function at the highest level in both the home environment and in society. Through skill-targeted practice, therapists provide exercises and training to strengthen underlying impairments and help the individual adapt to disabilities or changes in their living spaces to make everyday activities easier. An important factor for individuals recovering from brain injury, along with their families, to consider is selecting the most appropriate setting for rehabilitation. Many options are available: Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Outpatient (PHIDBIR-O), Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Home Based (PHIDBIR-HB), Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Day Program (PHIDBIR-DP), Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Hospital (PHIDBIR-H), and Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Residential (PHIDBIR-R) which are long-term supportive living programs for individuals who require

ongoing 24 hour supports, independent living centers, club-house programs, school-based programs for children, and others.

Definition of Terms

It is important to define the key terms that are used throughout this study. As briefly reviewed earlier in this chapter, those terms that reference the type of brain injury sustained include *acquired* brain injury (ABI) and *traumatic* brain injury (TBI). An ABI is an injury to the brain which is not hereditary, congenital, degenerative, or induced by birth trauma (BIAA, 2012). Acquired brain injury takes place at the cellular level within the brain, therefore, it can affect cells throughout the entire brain which is in contrast to traumatic brain injury, in which specific areas of the brain are injured. TBI is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force (BIAA, 2012).

The term *rehabilitation* refers in this study to the practice of restoring individuals to good health or useful life through therapy and education.

Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Residential (PHIDBIR-R) Program is the label used to describe a 24-hour, seven-day a week rehabilitation programs delivered in an environment that is not a hospital, but is a home-like and community-based environment of care. Healthcare companies that have created, provided, and managed a PHIDBIR-R rehabilitation environment, the environment focus of the current research, strive to provide the most effective therapeutic interventions, supports, and services that are shown to contribute to maximum functional gains. Indeed, rehabilitation programs provided in a PHIDBIR-R environment are to be judged on their ability to produce these improvements in function (Willer, Button, & Rempel, 1999).

Statement of the Problem

While research efforts have focused on demonstrating positive outcomes as a result of participation in PHIDBIR-R programs and the systematic study of PHIDBIR-R environments, the identification of specific variables that are provided by these PHIDBIR-R programs that significantly contribute to improvement in function remains untouched. (Salazar et al., 2000; Vanderploeg et al., 2008;

Ponsford, Harrington, Olver, & Roper, 2006; Prigatano, et al., 1994; Cicerone, Mott, Azulay, & Friel, 2004; Willer et al., 1999). To provide effective rehabilitation, it is essential that providers of and practitioners working in PHIDBIR-R environments include variables that have been shown to positively relate with functional recovery in the delivery of their rehabilitation techniques, environments of care, support, and services. Currently, rehabilitation companies, therapists, individuals, and families do not have access to these data to make informed decisions about program creation, implementation, assessment, enhancement, and program choice. And while several PHIDBIR-R programs report that they are producing positive outcomes (NeuroRestorative 2013b; ReMed, 2013; Bancroft, 2012), data are still missing. That is – *how* do these environments of care produce positive functional outcomes?

Furthermore, research has focused on quantitative analysis of specific programmatic techniques or environments and has ignored the wealth of potential data in collection and analysis of qualitative data. Including the qualitative method of inquiry may prove powerful in cultivating our understanding of the PHIDBIR-R experience by individuals and families, and how these experiences may enhance and advance our understanding of measured functional improvements.

Purpose of the Study

The purpose of this mixed methods, explanatory design study is to determine the specific constructs in one type of environment of brain injury rehabilitation - PHIDBIR-R programs - that have positively influenced measureable gains in function. Using a participant selection variant design (Creswell & Plano Clark, 2011), the investigation involves identification of those individuals who have participated in a PHIDBIR-R program and have shown the greatest progress in functional gain; all done for the a greater effort of informing and continually developing successful PHIDBIR-R programs. Examination of those individuals who have been least successful may also provide valuable insight in determining program variables, but is beyond the scope of this initial study. Improvement in function will be determined via quantitative analysis using an objective, psychometrically valid outcomes measurement system, the Mayo-Portland Adaptability Inventory-4 (MPAI-4). The current study also

involves an intensive interviewing technique to explore, in detail, the identified participants' and their family members' experience of the rehabilitation process.

A secondary goal of the current research project is to better understand the methodology process itself as specific to the brain injury arena - how qualitative interviews with brain injury survivors and their families treated in a PHIDBIR-R program contributes to a more comprehensive and nuanced insight regarding the survivors' functional improvement.

Lastly, the current study aims to promote action in applying the identified constructs as pillars of inclusion in the PHIDBIR-R programs that the principle investigator develops and manages. Results from this investigation carry important implications for the development and practice of providing PHIDBIR-R programs as a vehicle for optimizing functional improvement following brain injury.

Research Question

The primary question guiding the current research project is: Which specific constructs of Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Residential programs contribute to an individual's gain in function?

Overview of Procedures

This study uses a mixed methods methodology to identify the variables of a PHIDBIR-R program that are significantly related to functional recovery from brain injury. In order to identify those individuals who have been most successful in their functional recovery, the study will use a participant selection variant of an explanatory research design and use quantitative analysis via repeated-measures change scores from the Mayo-Portland Adaptability Inventory-4. Qualitative analysis, inclusive of participant and family member interviews, will be used to generate data concerning the details of individual PHIDBIR-R program constructs that are associated with functional improvement from baseline following the brain injury. The overarching goal of the current research is to determine best practice guidelines for PHIDBIR-R programs and include significant variables emerging as experiences across participants with positive functional gains.

Significance of the Study

The outcome of this research will represent a model that describes the constructs, their density, scope, direction, and relationship to one another. With real-life implications in serving brain injury survivors, this model must represent one that readers can place confidence in as being derived from sound methodology and technique that demonstrates sufficient rigor of analysis. The methods as described above are well-founded in research as supportive for instilling reader confidence (Creswell & Plano Clark, 2011).

Limitations

The current study focuses on absolute magnitude of changes in outcomes scores and does not take into consideration the rate of change. Testing occurs at admission and discharge only, so the study cannot identify *when* during the rehabilitation process the biggest changes occur. Data specific to participant history prior to admission to the PHIDBIR-R program inclusive of highly detailed injury characteristics, including the amount and type of rehab services received before admission, may not be available for all participants and therefore, cannot be included in analysis. The research does not account for spontaneous recovery following brain injury. Participants of this study are limited to the experiences they have had at one PHIDBIR-R program provided by one company that operates multi-site PHIDBIR-R environments of care, which may reduce the generalizability or transferability of the findings. While these limitations exist, the research will glean useful information to contribute to the research question. The study is important to pursue.

Overview of the Dissertation

Chapter I provides an overview of the current research, inclusive of the definition of brain injury, the mechanisms of brain injury, incidence, and costs. The Chapter also reviewed how brain injuries are studied and how rehabilitation is provided for individuals recovering from brain injury followed by a definition of key terms that will be used throughout the research, an outline the problem in what current research does not address in the PHIDBIR-R program environment of care, and the purpose of the current study. The research question was stated, an overview of the methodology of the research procedure was

provided, and the significance of the study was described. The chapter concluded by noting the study's limitations.

Chapter II begins with a short, historical review of programs specializing in the rehabilitation of individuals with brain injury. It continues with an examination of the program components and models of these rehabilitation environments, provides examples of variability among providers, and describes how this level of care fits within the rehabilitation continuum. Chapter II then reviews previous studies' reports on PHIDBIR-R programs continues to identify recent trends in outcomes measurements and effectiveness as they are relevant to the current investigation. The remainder of Chapter II concludes with the demonstrated need for the systematic study of key elements of PHIDBIR-R programs in the facilitation of positive functional gain following brain injury. The review of the literature establishes the need for meaningful and relevant research in this area and serves as the basis for the conceptual framework of the current study.

Chapter III provides a brief review of mixed methods inquiry and describes in detail the research methodology used in the current study. The participant selection, data collection tools, and protocols are described. Data analysis methods and research techniques to increase reliability and reader confidence in the methodological rigor are explained.

The results of the data analysis are described in Chapter IV. Major reoccurring themes are also provided and examined.

Chapter V is the study's final chapter and contains a discussion of the results of the study inclusive of a proposed model of PHIDBIR-R program and variable inclusions related to functional recovery from brain injury. Methodological considerations and the study's limitations are provided. Implications are discussed. The chapter concludes with recommendations for future research.

CHAPTER II

Review of the Literature

Introduction

Chapter II provides a review of the literature and establishes a context for the proposed research inquiry. The review begins with a short, historical review of programs specializing in the rehabilitation of individuals with brain injury. It continues with an examination of the program components and models of these rehabilitation environments, examples of variability among providers, and description of how this level of care fits within the rehabilitation continuum. Chapter II then reviews previous studies' reports on Post-Hospital Inter Disciplinary Brain Injury Rehabilitation –Residential programs (PHIDBIR-Rs) and includes outcome measurements and reports used to evaluate such programs. The review continues to provide recent trends in outcomes measurements and effectiveness which are relevant to the current investigation. The remainder of Chapter II reviews a number of broad topics which provide context for the study, including: relevant studies on individuals' perception of acquired brain injury residential rehabilitation and time-since-injury access to rehabilitation. Chapter II concludes with the demonstrated need for the systematic study of key elements of PHIDBIR-Rs. This review of literature establishes the need for meaningful and relevant research in this area while also serves as the basis for the conceptual framework of the current study.

A Short History of Programs Specializing in Rehabilitation Services for Individuals with Brain Injury

Specialized programs in the United States providing comprehensive rehabilitation for individuals with brain injury find their origins in the Arab-Israeli War of 1973 (Ben-Yishay, 1996). In the aftermath of this war, the Israel Department of Defense enlisted the help of Howard A. Rusk for assistance in treating some 250 brain-injured veterans. Rusk was a prominent physician and founder of the Institute of Rehabilitation Medicine at the New York University Medical Center. He was active in the Health for Peace movement in the 1950s and supported the efforts of the United States regarding the participation in

rehabilitation medicine in international affairs. The assignment was delegated to one of Dr. Rusk's associates, Yehuda Ben-Yishay, Ph.D (Ben-Yishay, 1996).

As a former Israeli, Dr. Ben-Yishay had trained with Dr. Kurt Goldstein, who played a leading role in establishing the relationship between the brain and behavior (Ben-Yishay, 1996). Ben-Yishay noted that while soldiers fighting in the Arab-Israeli War of 1973 were able to regain some functional abilities using traditional rehabilitation techniques, they remained unable to resume productive lives because of their cognitive limitations, behavioral problems, and lack of awareness regarding their deficits. Realizing that rehabilitation for such injuries would require a radically different therapeutic approach, and that no such program existed in the United States, Dr. Ben-Yishay used the results of his work in Israel to obtain federal funding for a five-year clinical research study at New York University's Rusk Institute. There, he developed a brain injury day treatment program, designed to help relatively high-functioning adults cope with the residual deficits following a brain injury. The program was developed at a time when, during the previous decade of the 1970s, super highways proliferated America and high-speed vehicular accidents began to account for the largest share of traumatic brain injuries (TBIs) (Liu, Chen, & Utter, 2005).

Ben-Yishay's holistic approach to rehabilitation involved a multi-disciplinary approach, targeting functional skill development, community integration, and adjustment to deficits (Ben-Yishay & Diller, 1981). He and his colleagues established the day program at New York University in which individuals were able to participate in an outpatient model of care. This model required that all participants provide their own accommodations while attending the day program. Independent completion of activities regarding daily living and self-transportation to this program were challenging for some individuals who presented an inability to safely complete these activities without assistance (Osborne, 1998).

In 1997, the Center for Comprehensive Services was established in Carbondale, Illinois as a specialized post-acute brain injury program following hospitalization (NeuroRestorative, 2013a). The program was developed and implemented by a small group of therapists from Southern Illinois University who hypothesized that a holistic, multi-disciplinary program that targets functional skill development,

community integration, and adjustment to deficits may be best accomplished in an inpatient model of care where supports and services were provided twenty-four hours a day, seven days a week. The program's architects believed a residential model that provided a home-like environment within a community would allow for a heightened development of functional skills needed for independence. The program was opened across from the Southern Illinois University campus and remains active today (NeuroRestorative, 2013a).

In the late 1980s and early 1990s, additional privately held, post-acute programs specializing in the rehabilitation of individuals with brain injury in a residential environment were established. Many very large campus-based programs thrived financially in Florida, New York, New Hampshire, Massachusetts, Michigan, Wisconsin, Arkansas, Texas, Louisiana, and California (Winslade, 1998). While individual participant improvements were described by therapist notes, no state or federal requirement existed for these programs to collect or report program outcomes, or to demonstrate any functional changes from the time of admission until discharge from the program (Winslade, 1998).

Post-Hospital Brain Injury Rehabilitation

The above review has described a historical development of after-hospital programs in which rehabilitation is provided following acute hospitalization. Post-hospital rehabilitation requires that the medical issues affecting an individual's ability to sustain life have resolved, or at least stabilized to a point which permits the individual to participate in at least three hours of therapy daily. Individuals who access a specialized brain injury *residential* model (a 24 hour inpatient model) typically present a greater number of residual functional deficits, often reflective of a moderate to severe brain injury (Brasure et al., 2012). In contrast, those who are discharged to their home from hospital care following their injuries typically sustained a more mild form of brain injury. In addition, individuals entering a residential model of care may present at a greater time since their injury was sustained with residual sequelae of brain injury continuing to challenge their safety, abilities, participation, adjustment, and independence when compared to those who discharge directly home from the hospital (Glenn, Rotman, Goldstein, & Selleck, 2005). A specialized brain injury residential model of care provides rehabilitation in a home and local community

environment. As such, the model requires that an individual be medically stable and no longer requiring hospital-level care. The Centers for Medicare and Medicaid Services (CMS) name post-hospital care as “post-acute care” and provide a description of individuals who need additional help recuperating from an acute illness or serious medical procedure (CMS, 2013a). Perhaps that is why the term *post-acute* has frequently been used to describe these programs. The current researchers prefer the term “post-hospital” to avoid confusion with rehabilitation hospital level care. It is noted that Skilled Nursing Facilities (SNFs) also serve individuals who have been discharged from a hospital level of care and as such are in a post-hospital state. However, SNFs are nursing homes which provide long-term custodial care for people, often the elderly, who are unable to care for themselves either at home or in an assisted living facility. While there is often a rehabilitation component to these institutions through which patients may receive skilled therapies, SNFs do not specialize in the treatment of brain injury and most often care for an over 65 year old clientele, providing 24 hour supervision, meals, activities, and health management support for their residents (Marak, 2015). Post-Hospital Brain Injury Rehabilitation is a term broadly associated with a model of rehabilitation provided after medical treatment for brain injury has been delivered by an acute hospital (Lewis & Horn, 2013).

Rehabilitation is broadly defined as a problem-solving educational process aimed at reducing disability and handicap experienced by someone as a result of disease or injury (Wade, 1992). Currently, there is no consensus regarding a classification system of rehabilitation interventions and programs (Turner-Stokes, Nair, Sedki, Disler, & Wade, 2011). Programs may be described in terms of setting and content. In their review of brain injury treatment models, Turner-Stokes, Nair, Sedki, Disler, and Wade (2011) note that rehabilitation settings may include:

- in-patient settings – where rehabilitation is delivered in the context of 24-hour care, which may be in a hospital ward or a specialist rehabilitation unit;
- out-patient or day treatment settings – which again may occur in a hospital environment, a local community venue (such as a day center), or a specialist rehabilitation environment;

- domiciliary or home-based – focused around the patient’s own home and local community.

Experts in the field of brain injury rehabilitation believe that comprehensive, Inter-Disciplinary, post-hospital rehabilitation is the best approach for addressing impairments resulting from moderate to severe TBI (Brasure et al., 2012). However, most studies reviewed provided limited definitions of the examined therapeutic intervention programs. The Department of Health and Human Services’ Agency for Healthcare Research and Quality notes that definitions or details about the content of the interventions in studies appears to improve over time (e.g., more recent studies have provided improved definitions) but that generally, post-hospital rehabilitation programs address sustained impairments across physical, cognitive, and affective/behavioral domains and strive to improve functioning and participation (as cited in Brasure et al., 2012).

Research published in the 1970s and 1980s, began to demonstrate that isolated discipline or domain-specific training was insufficient for comprehensive rehabilitation of individuals presenting with brain injury, and that insurance and public payers were becoming more discriminating in providing financial support for individuals with brain injury entering after-hospital rehabilitation programs (Braunling-McMorrow, Dollanger, Gould, Neumann, & Heilingenthal, 2010). Such declining financial support prompted clinicians to begin adopting holistic approaches to TBI rehabilitation (High, 2005). While a standard definition for these comprehensive programs does not exist, the current preferred approach is Inter-Disciplinary, with treatments (including those for comorbidities) integrated across disciplines or impairment domains (Brasure et al., 2012). Turner-Stokes et al.’s 2011 systematic review of Inter-Disciplinary rehabilitation post brain injury defines Inter-Disciplinary as more than one discipline working in coordination. These programs are described by many different terms, including “multi-disciplinary,” “Inter-Disciplinary,” “comprehensive,” “holistic,” “neurobehavioral,” “neurorehabilitation,” and “integrated.” These teams of rehabilitation professionals often include physiatrists, neurologists, neuropsychologists, clinical psychologists, physical and occupational therapists,

speech-language pathologists, recreational therapists, social workers, rehabilitation nurses, and technicians (Brasure et al., 2012).

A significant research challenge exists, in that Inter-Disciplinary programs differ in their settings, components, emphases, and degree of structure. It is an individual's impairments which may largely determine the composition, intensity, and duration of rehabilitation. An additional challenge in defining this environment and treatment paradigm(s) is that while there is a general understanding that comprehensive programs are comprised of many different professionals working as a team, it is difficult to find program descriptions that specify percentages or doses of the various available therapies. Programs are often variable and developed as a function of patients' individually specific needs. Inter-Disciplinary rehabilitation programs for brain injury lack a clear and consistent taxonomy, making systematic study of improvements associated with different models difficult (Turner-Stokes et al., 2011; Brasure et al., 2012; Glenn et al., 2005).

Turner-Stokes et al. (2011) states the crux of comparative studies among these programs: "It is probable that the actual content of any two programmes within the same category [post-hospital, Inter-Disciplinary brain injury rehabilitation] varied greatly, and also that similar programmes may have been given different labels... Consequently... it is difficult to describe" (p. 7). If this level of rehabilitation cannot even be described across settings, geography, and program inclusions, comparative studies cannot be effectively completed.

Post-Hospital, Inter-Disciplinary Brain Injury Rehabilitation – Residential (PHIDBIR-R)

PHIDBIR-R programs may be described as a sub-type of an inpatient program as described by Turner-Stokes et al. (2011). Rehabilitation programs that specialize in brain injury and provide 24 hour per day treatment after discharge from the hospital have several labels. Some of the terms used to reference these programs include: "Post-Acute Rehabilitation Program," "Residential Community Reintegration Programs," "Community-Integrated Brain Injury Transitional Program," "Post-Acute Brain Injury Rehabilitation Program," and several other varieties of these themes. Most labels used to describe these programs include some variety in ordering of the concepts inclusive of:

- after-hospital, indicated by use of “post-acute,” “community,” “community-based,” or “community-integrated;
- Inter-Disciplinary, meaning more than one discipline working in coordination across disciplines and impairment domains;
- twenty-four hour per day, seven-day per week environment of care, indicated by use of “residential” or “in-patient;”
- provision of treatment to a specific diagnosis or population, indicated by use of “brain injury,” “neurologic,” “neurorehabilitation,” or “neurobehavioral;”
- a verb indicating the restoration of improved functioning as through therapy and education and indicated by use of “rehabilitation,” “transitional,” or “neurorehabilitation;”
- a noun to indicate an environment, indicated by use of “program,” “facility,” or “care” (Ashley, Persel, Clark, & Krych, 1997; Bornhofen & McDonald, 2008; Geurtsen et al., 2011; Malec & Basford, 1996; Zgaljardic, Yancy, Temple, Watford, & Miller, 2011).

For the purposes of the current research, the term Post-Hospital Interdisciplinary Brain Injury Rehabilitation – Residential (PHIDBIR-R) will be used, as it reflects key components of these programs as described by regulators, payers, and accrediting bodies. While the Centers for Medicare and Medicaid Studies (CMS) does not recognize post-hospital rehabilitation as a distinct category, some agreement among state Medicaid payers exists regarding components of post-hospital rehabilitation as it applies to recovery specifically from brain injury. For example, the Texas Department of Assistive and Rehabilitative Services (DARS) defines post-acute brain injury services as advanced rehabilitation services provided through an Inter-Disciplinary team approach, with services based on an assessment of the individual's cognitive deficits. DARS further indicates that the goal of post-acute rehabilitation treatment is to achieve functional changes in a consumer with a brain injury by reinforcing, strengthening, or re-establishing previously learned patterns of behavior and/or establishing new patterns of cognitive activity or compensatory mechanisms (DARS, 2013). Thus, the term “Post-Hospital Rehabilitation” appears to provide an apt description.

The Commission on the Accreditation of Rehabilitation Facilities (CARF) is a private, non-profit organization that accredits healthcare human services across the lifespan and continuum of care. Founded in 1966, CARF accreditation is one means by which a brain injury rehabilitation program can demonstrate commitment to quality and accountability for services provided for individuals with brain injury. The process of accreditation reviews the functioning and practices of an organization, their program, and services. CARF has engaged with brain injury service providers and individuals with brain injuries since the early 1980s to seek quality and accountability throughout the continuum of services provided for individuals with brain injuries. The CARF standards have been developed over the last 47 years with input from consumers, rehabilitation professionals, state and national organizations, and funders. Every year, the standards are reviewed and new ones are developed to keep pace with changing conditions and current consumer needs. CARF (2013) defines a Brain Injury Specialty Program as a program designed to deliver services that focus on:

...the unique medical, physical, cognitive, communication, psychosocial, behavioral, vocational, educational, accessibility, and leisure/recreational needs of persons with acquired brain injury.

The program integrates services to:

- Minimize the impact of impairments and secondary complications.
- Reduce activity limitations.
- Maximize participation, including wellness, quality of life, and inclusion in the community.
- Decrease environmental barriers.
- Promote self-advocacy.

A Brain Injury Specialty Program recognizes the individuality, preferences, strengths, and needs of the persons served and their families/support systems. It provides access to information, services, and resources available to enhance the lives of the persons served within their

families/support systems, communities, and life roles and supports their efforts to promote personal health and wellness and improve quality of life throughout their lifespan.

The program demonstrates the commitment, capabilities, and resources to maintain itself as a specialized program for persons with acquired brain injury. A Brain Injury Specialty Program utilizes current research and evidence to provide effective rehabilitation and supports future improvements by advocating for or participating in brain injury research.

A Brain Injury Specialty Program partners with the persons served, families/support systems, and providers from emergency through community-based services to foster an integrated system of services that optimizes recovery, adjustment, inclusion, participation, and prevention. A Brain Injury Specialty Program engages and partners with providers within and outside of rehabilitation to increase access to services by advocating for persons who have sustained a brain injury to regulators, legislators, educational institutions, research funding organizations, payers, and the community at large. (p. 233)

While CARF's definition of a Brain Injury Specialty Program is not prescriptive as to the specific methods, type, intensity or frequency of treatment, or philosophy of care essential to support the needs of individuals with brain injury, it well describes the components of a program focused on improvement of function from baseline for individuals affected by brain injury at any point along the healthcare continuum and throughout an individual's lifespan. Thus the term "Brain Injury Program" is an apt description.

CARF (2013) further defines a Residential Rehabilitation Program as an environment designed to provide individuals the opportunity to achieve predicted outcomes which are focused on home and community integration and engagement in productive activities. The programs provide opportunities for the increase or maintenance of functional and social performance and health, and occur in residential settings, which may be transitional or long-term in nature (CARF, 2013). Thus, the term Residential Rehabilitation Program proves a fitting description.

By combining the terms which describe key elements of these programs: Post-Hospital, Rehabilitation, Inter-Disciplinary Brain Injury Program and Residential, I can label these programs as Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Residential programs (PHIDBIR-R programs). This term proves most inclusive of all elements of the environments of care in which I pose the research question and will be used throughout this study. PHIDBIR-R programs differentiate from the rehabilitation environment in which participants engage from those hospital or unit-based in-patient programs (which may be termed PHMDBIR-IP); out-patient programs (PHMDBIR-OP) and domiciliary or home-based/community based programs (PHMDBIR-H&C).

How are PHIDBIR-R Programs Characterized in Studies?

There is great heterogeneity of PHIDBIR-R programs with models differing greatly from provider to provider (Winslade, 1998). Given the differences in ownership and the variety of rehabilitation philosophies, approaches and techniques, these programs vary greatly with respect to the setting, the frequency and intensity of treatment, length of stay, community access, nature and type of the therapeutic interventions, proportion of individual and group therapies, level of family participation, education and training of staff, cost, and innumerable other factors which may have an effect on individual outcomes (Turner-Stokes et al., 2011). Brasure et al.'s (2012) review of PHIDBIR-R programs specializing in treatment of TBI in adults cautioned that studies involving this type of treatment do not always adequately define intervention and control treatment. Programs are delivered in a variety of settings, including in-patient and out-patient rehabilitation centers, as well as in community and home-based settings. Most interventions do not appear to be theoretically based, nor constructed through evidenced based practice. However, references to certain models of care are frequently reported. Inter-Disciplinary rehabilitation programs, based on models originally described by Ben-Yishay (1996), are most frequently studied but rarely report efforts that demonstrate effective implementation of interventions, such as the availability of manuals or other documentation outlining the interventions, staff training, and/or methods used to demonstrate treatment provided (referred to as fidelity checks) (Brasure et al., 2012).

Studies that evaluated new models of care, compared different models of care, or assessed particular components of PHIDBIR-R programs may lack consistent taxonomy, but have described a number of program characteristics (Sarajuuri, Kaipio, & Koskinen, 2005; Shiel, Hawe, & Gold, 2008; Vanderploeg et al., 2008; Willer et al., 1999; Ylvisaker, Hanks, & Johnson-Greene, 2012; Ylvisaker et al., 2005; Cicerone et al., 2004; Cicerone, Dahlberg, Malec, Langenbahn, & Felicetti, 2005; Cicerone et al., 2011). Programs typically engaged a similar variety of disciplines (Rehabilitation Nursing, Speech-Language Pathology, Occupational Therapy, Social Work, Physical Therapy, NeuroPsychology or Clinical Psychology, Rehabilitation Medicine) and utilize models of care originally described by Ben-Yishay (1996), emphasizing cognitive rehabilitation and an integrated approach across disciplines. These studies also described therapies delivered in a similar manner, in which small groups of five to eight participants progressed through a rehabilitation program together. These programs typically involved substantial group therapy when compared to standard, non-residential rehabilitation programs. A variety of therapy types were provided, with vocational rehabilitation as a core component (Sarajuuri et al., 2005; Shiel et al., 1988; Vanderploeg et al., 2008; Willer et al., 1999). Despite their many similarities, interventions based upon this model varied in duration of treatment from 32 days up to three years (Vanderploeg et al., 2008; Willer et al., 1999).

Generally, residential environments are non-hospital based and provide access to community activity for the purposes of generalizing skills learned in treatment to the community where they may be practiced within the context of functional use. Generalization of skills learned in one environment to the environment in which they are used is considered by some to be best practice in the regaining of cognitive skills (Ylvisaker et al., 2012; Ylvisaker et al., 2005; Cicerone et al., 2004; Cicerone et al., 2005; Cicerone et al., 2011). The programs often self-describe as providing integrated cognitive, emotional and behavioral self-management, social, leisure, and vocational treatment planning (Malec & Basford, 1996). However, it can be purported that the coordination of services, disciplines providing these services, components of a program including type of treatment and method of delivery, number of therapy hours per week, duration of the program, staff training, and fidelity checking (to demonstrate that a treatment

has been provided) vary greatly, as these individual component pieces are not described in studies (Turner-Stokes et al., 2011).

To illustrate this wide variation in PHIDBIR-R programs, and lack of homogeneity, a comparison of two different programs in which the current researcher has worked is described (see Table 1). Program “A” is set within a rural, secluded area and provides a sixty-acre campus of twelve cabins with eight participants in each cabin. Participants’ days are structured around cohort schedules during which each participant is required to attend four 45 minute group sessions focused on a given skill set (e.g. Orientation Group, Banking and Budgeting Group, Cognitive Skills Group, or Exercise Group) and periodic one-on-one treatment sessions provided by licensed clinicians of differing disciplines (perhaps 2 to 6 times a week). The group sessions are provided by “Extenders,” unlicensed staff members who complete one week of initial training in direct care support and general sequelae of brain injury, one week of mentoring and quarterly day-long training thereafter, and are monitored by licensed clinicians. The group curriculum is not standardized and reported in a manual, and there is no system in place to report planned activity versus activities that occurred. The program’s coordination is supplied by the Clinical Director who is a NeuroPsychologist. The average length of stay is 18 months.

PHIDBIR-R program “B” is a set in a three-bedroom home within a dense residential housing area with neighboring homes. The day is structured with small group activities within the home that focus on home keeping and maintenance activities with cuing and supports provided by Extenders. In addition to group participation, functional daily living activities such as shopping and recreational activity as well as day treatment access where center-based rehabilitation is provided in a one-to-one format by licensed clinicians with across at least four different disciplines. The Extenders have received one month of training, are certified in a behavioral crisis intervention technique, and participate in ongoing (biweekly) training activities. Extenders are fluent in each participant’s individual goals and provide data to the licensed clinicians representing results of daily protocols designed to provide maximum practice of a particular identified skill. The group curriculum is standardized in a program manual and there is a system utilized to report planned activity versus activity that has occurred. The program’s coordination is

supplied by the Clinical Director who is a Psychiatrist. The average length of stay is six months. Table 1 provides a view of these two differing PHMDBIRP-Rs.

Table 1

Example of Two Differing PHIDBIR-R Programs

Differences	PHIDBIR-R “A”	PHIDBIR-R “B”
Physical Environment (Setting)	Rural campus-based: Twelve cabins, eight participants per cabin, shared rooms	Dense community-based: One family-home, three participants, single rooms
Coordination	Neuropsychologist	Psychiatrist
Treatment Components	Small group, limited individual focus, delivered in center, rare community access	Small group, daily 1:1 treatment, delivered in home and treatment center, daily community access
Program Delivery Method	Extender provided therapy overseen by licensed clinicians	Licensed clinician provided therapy with augment opportunities for extenders
Treatment Hours/Day (Average)	0-2 hours delivered by licensed clinicians, 6 hours group activity lead by extenders	At least 4 hours by licensed clinicians, 6-8 hours lead by extenders trained in specific protocols
Program Duration (Average)	18 months	6 months
Disciplines	NeuroPsychology, OT, ST, PT, Non-certified Behavioral Specialist, RN	NeuroPsychology, OT, ST, PT, CRT, RN, LCSW, certified Behavioral Analyst
Staff Training	One week staff orientation, training includes: .5 hour presentations by disciplines, one week mentoring, one day quarterly training thereafter	One month of staff orientation, training includes: three days behavior certification, two weeks of video and in vivo participatory training, two weeks mentoring, one hour biweekly training

Manualized Tx?	No	Yes
Fidelity Checking	Scheduled therapy not verified	Scheduled therapy verified daily

As these two examples of PHIDBIR-R programs showcase, there is great variability among programs which exist within the PHIDBIR-R category, making comparison of outcomes challenging.

Outcome Measurements

For the purposes of the current research, I will use the Center for Outcomes Management in Brain Injury's [COMBI] notion of "outcomes measurement" as tools that are used to assess change in an individual over time in meaningful areas of a person's life in a way that informs collaborative decision-making surrounding treatment (COMBI, 2012). Outcome measures are differentiated from other kinds of measures of enduring characteristics such as personality traits, transient processes such as thoughts or expectations and satisfaction with treatment. Outcome measurements are an important consideration in brain injury rehabilitation for the purposes of evaluating efficiency and efficacy in both PHIDBIR-R programs and individual participant results and progress.

The heterogeneity of PHIDBIR-R programs as described above poses challenge to evaluating programs using traditional interventional or randomized control-based methodologies (Whyte, 2002). These problems are not unique to the PHIDBIR-R industry, but are similarly faced by rehabilitation programs and many medical specialties, and have been recognized by the Medical Research Council (MRC) in its approach to evaluation of complex interventions (Craig et al., 2008; Shiel et al., 2008). There is no agreed upon classification of outcome measures concerning research inquiring into efficacy of rehabilitation following brain injury, regardless of the theory/model, program type, setting, and delivery methods (Brasure et al., 2012).

Studies of PHIDBIR-R Programs Using Outcome Measurements

Studies that have assessed pre-specified patient-centered outcomes that have reflected or incorporated broad outcomes relative to participation, quality of life, or functioning

within a community setting for individuals participating in PHIDBIR-R programs have used a variety of outcomes to determine changes and progress following treatment. Some studies have focused on an increase in productivity as measured by return to gainful employment or fitness for military duty at one year post-treatment (Salazar et al., 2000; Vanderploeg et al., 2008). Two of these studies used an active-duty military or veteran population with moderate to severe closed head injury treated three to six months post-injury.

Salazar et al.'s (2000) study included 120 individuals and provided either an intensive, standardized cognitive rehabilitation program or a limited home rehabilitation program. Vanderploeg et al.'s (2008) study included 366 individuals and compared a cognitive-didactic versus functional-experiential treatment programs. The study used randomized control trials and treatment was provided for 3 to 8 week programs. While productivity increases were noted in both groups, differences in productivity measures were noted between the groups.

Another similar study used community-based employment at six months post-treatment as an outcome indicator for 68 individuals (Cicerone et al., 2008). The sample included chronically impaired patients with moderate to severe TBI, using a cohort study design and intervention of a PHIDBIR-R program versus a non-specific inpatient hospital or outpatient rehabilitation program for a sixteen week duration. Findings indicated a statistically significant higher proportion of the PHIDBIR-R program group were employed at the end of treatment, but that there were no differences between these same groups six months post-treatment.

A similar research question about employment was asked using a study design that included a controlled, individually matched cohort trial of 77 individuals (Ponsford et al., 2006). This study also found no significant differences between groups in terms of employment outcomes. Sarajuuri, Kaipio, and Koskinen's (2005) study expanded the definition of productivity to include working, volunteering, or studying and measured these outcomes two years post-participation for 19 individuals who completed a PHIDBIR-R program and 20 who received traditional rehabilitation in a hospital setting or outpatient clinic. This study found 89% of the patients treated in PHIDBIR-R environment were productive

compared with 55% of the controls treated in the more traditional setting. An earlier study used 18 individuals who completed a PHIDBIR-R program and a cohort of 17 individuals who did not, finding that 50% of the PHIDBIR-R program participants maintained productivity (as defined by employment) at least 75% of the time following rehabilitation (time frame unspecified), compared to 36% of those who did not participate in a PHIDBIR-R program (Prigatano et al., 1994).

The above review of productivity as an outcome measure of participation in a PHIDBIR-R program may be recognized as inconclusive. Some of the studies enhanced the field's understanding that outcomes based on productivity as measured by employment did not correlate with durable employment status, while other studies suggested that productivity outcomes did correlate with durable employment status. The studies reviewed above did not provide specific information on the constructs of the treatment or the details of the PHIDBIR-R program that may have affected employment outcomes. These studies could have enriched our understanding of factors contributing to durable employment in both the treatment and control groups had they gathered qualitative data of those participants who were successfully employed post-treatment and for those who were not determined to be successfully employed.

One study, however, involving 38 PHIDBIR-R program participants that compared a historical control group of 38 TBI individuals who did not receive this form of residential rehabilitation found not only that a greater number of the treatment group were productive (e.g., a student, a worker, or both) compared with the group who received a traditional, non-residential form of treatment, but also noted that a "good or excellent working alliance with the rehabilitation staff was significantly related to a positive productivity status" (Prigatano et al., 1994). While this study provides the first insight into identification of specific variables related to functional recovery from brain injury as part of a PHADBIR-R program, it is anecdotal. The authors may have probed this notion and gained some valuable insight into core program constructs that contribute to successful outcomes. Use of outcomes measurement systems that solely capture productivity pre- PHIDBIR-R program and following completion may not be sensitive or

inclusive in the measuring of changes in the different areas of persisting sequelae of deficits most often observed to continue following brain injury.

Several studies have reported community integration as an outcome measurement via the *Community Integration Questionnaire–CIQ* (Cicerone et al., 2008; Cicerone et al., 2004; Hashimoto Okamoto, Watanabe, & Ohashi, 2006; Willer et al., 1999). The results demonstrated greater improvement in community integration and productivity as measured by the CIQ in the group receiving the PHIDBIR-R treatment at six months to one-year follow-up, while the functional gains and the level of community integration were maintained. While these studies contributed to our knowledge that community participation is a construct that can be improved and measured by the CIQ, they did not detail the means by which the PHIDBIR-R programs provided opportunity for improvement of these skills and outcomes, but merely listed the number of hours of clinical services provided weekly (4 to 25 hours).

Again, while the outcome measurement of community integration demonstrated change from baseline, the studies did not seek to determine which constructs of the PHIDBIR-R program were most closely associated with those participants who were most successful in achieving the highest outcomes. The descriptions of the programs included vague references to therapeutic interventions taking many different forms, in different locations, provided by relevant team members. These studies could have contributed to program improvement by studying the most successful participants and determining which program constructs were associated with their success. The CIQ however, unlike productivity outcome measurement systems, does seek to evaluate individuals on more than just one domain. Steps in the right direction to studying program improvement are being made; however, data paramount to identification of key constructs influencing participant success is lacking.

The CIQ was developed by Barry Willer, Ph.D. and a group of professionals and consumers to provide a measure of community integration after traumatic brain injury that could be used in the TBI Model Systems program, funded by the National Institute on Disability and Rehabilitation Research (NIDRR). They used the following design criteria: brevity, suitability for use in an in-person or telephone interview, conducted with the person with TBI him/herself (preferably) or with a proxy, focus on

behaviors rather than feeling states, no biases resulting from age, gender or socioeconomic status, sensitive to a wide variety of living situations, and value neutral. The scale consists of 15 items relevant to living, loving and working, or more formally: home integration (H), social integration (S), and productive activities (P). It is scored to provide subtotals for each of these, as well as for community integration overall. The basis for scoring is primarily frequency of performing activities or roles, with secondary weight given to whether or not activities are done jointly with others, and the nature of these other persons (for example, with or without TBI). In its current format, the CIQ can be completed by either the person with a TBI or a designated proxy, in about 15 minutes. The most common method of data collection is an in-person interview, but telephone interviewing is quite frequent, and the TBI model systems also utilize self-administered CIQs. While the CIQ is an improvement on outcomes measurements compared to those that score a single domain of functioning, it lacks the ability to measure safety and independence in many functional activities and adjustment to disability (Willer et al., 1999).

Other studies have developed in-house outcomes measurement tools. In 2000, the developers of CHART (Craig Handicap Assessment and Reporting Technique), designed and tested the CHART Short Form (CHART-SF). To reduce the number of questions in CHART a multi-dimensional analysis plan was designed. First, using data already gathered from a previous study, item-scale and item-total correlation coefficients were calculated for each scale. Second, regression analysis was performed on each subscale with the dependent measure being the scale score and the variables contributing to the subscale acting as the predictor variables. It was hypothesized that each subscale score could be accurately predicted by fewer items. With two exceptions, the only variables that were selected to be in a subscale were those that entered into a stepwise regression model together explaining over 90% of the variance. Third, once the items had been selected for each subscale, the items were re-scored. Each subscale was computed to have a maximum score of 100, which indicates no handicap in that domain. Furthermore, efforts were made to keep all of the score weightings of the variables proportionate to the original weightings. Fourth, the CHART Short Form items and scoring were evaluated on 1800 persons that contributed to the Behavioral Risk Factor Surveillance System's survey of Colorado residents. As a result, the CHART SF has 19 items

that yield the same sub-scales as the original CHART (32 items). There is sufficient evaluation of the CHART-FS to determine it as a reliable and valid measure for examining community integration in persons with spinal cord injury (Golhasani-Keshtan, Ebrahimzadeth, Fatti, Soltani-Moghaddas, & Omid-Kashani, 2013; Gontkovsky, Russum, & Stokic, 2009).

While this outcomes measurement tool appears to well capture community integration, it misses the opportunity to reflect changes in safety and independence in functional skills and adjustment to disability. One study used the CHART-SF, which asks raters to complete questions that pertain to social integration, productivity, mobility and physical independence. The research concluded that in many domains, there were no significant differences in the areas of employment outcomes, independence in personal and domestic activities of daily living, mobility and social integration as measured on the CHART-SF between those who participated in the PHIDBIR-R program and those in the control group, who had received conventional out-patient rehabilitation (Ponsford et al., 2006). The researchers concluded that the amount of therapy received by those who participated in the treatment group could not be quantified and sited this as confounding factor. The reader is left wondering, are these findings a shortcoming of an outcomes measurement tool which is not sensitive to the changes experienced by participants or are the findings a shortcoming of the PHIDBIR-R program which did not produce an environment in which improvements were achieved?

An in-house outcomes measurement tool, the *Functional Area Outcomes Menu (FAOM)* developed by Braunling-McMorrow the early 1980s is a behaviorally anchored 5-step scale rated by rehabilitation teams at three time periods, requiring ratings in 11 functional areas, including Residential Status, Level of Independence, Behavioral and Emotional Status, Community Participation, Level of Awareness, Vocational Endeavors, Educational Endeavors, Involvement in Vocational or Educational Endeavors, Level of Self-Managed Health, and Intimacy/Relationships and Global Quality of Life. A 2010 study found the PHMDBIR – R treatment model achieved significant functional gains of 1.5 levels for individuals with brain injury who presented as neuropsychologically-impaired adults with and without associated behavioral and substance problems (Braunling-McMorrow et al., 2010.)

Another recent study used an in-house developed outcomes measurement tool, the Pate Environmentally Relevant Program Outcome System (PERPOS) (Hayden et al., 2013). The PERPOS assesses three separate dimensions, including the individual's overall ability level across multiple domains (range 1-7), a measure of environmental distraction (measured on a 4-point scale), and a measure of structure inherent in the environment or activity (measured on a 4-point scale). The study evaluated functional improvement of a traumatic brain injury (TBI) after admission to a PHIDBIR-R program, where individuals (n = 1274) received comprehensive multi-disciplinary treatment five days per week, at six hours per day. The study focused on the time since injury and analysis of recovery by degree of impairment at admission. Individuals were admitted for treatment less than five years after a TBI and were assessed on the PERPOS outcome measure at least 3 times: at admission, during the treatment phase and at discharge. Individuals were then grouped by the time since injury and the severity of impairment at admission. The findings indicated that rehabilitation at the PHMDBIR – R program yielded significant gains in functioning, with 69% of all patients who demonstrated clinically meaningful gains. The time since injury had a significant impact on gains made in rehabilitation, with the zero to three months post-injury group outperforming each other group. The study concluded that rehabilitation received at a PHIDBIR-R program is associated with functional gains for individuals with TBI beyond what can be explained by undirected, spontaneous recovery. The PERPOS outcomes measurement tool is reported to correlate with the Mayo-Portland Adaptability Inventory-4 (MPAI-4), but to date, has only been reported in this single study.

Three recent studies used the MPAI-4 as an outcomes measurement tool. Lewis and Horn (2013) used the MPAI-4 to evaluate the efficacy of treating the residual deficits of 285 individuals with moderate to severe brain injury in PHIDBIR-R programs and identified, through a test-retest analysis, the 12 most often rated deficits causing the greatest interference with functional improvement. Of these skills, the cognitive deficits including memory, attention/ concentration, novel problem solving, and awareness of deficits were highly correlated with disruption in performing everyday societal roles. The study found that the impact of treatment for reducing the level of disability in these areas was highly significant and

improvement was significant even for the most chronic participants who were admitted to the PHIDBIR-R programs more than one year post-injury. The average length of stay at the treatment program was 27 months. The study concluded that PHIDBIR-R programs achieved significant reduction in disability from program admission to discharge as demonstrated by the changes in scores on the MPAI-4 from admission to discharge.

In a different study also conducted reported in 2013 by Lewis and Horn, of the researchers again used the MPAI-4 as an outcomes measurement tool to assess the level of functional disability reduction in 569 individuals who participated in PHIDBIR-R programs. The second study further described environments of care fitting the PHIDBIR-R program description as either a) a NeuroRehabilitation program providing active therapy five to seven days per week, b) a NeuroBehavioral program providing active therapy focusing on behavior self-management and community integration, or c) a Supported Living program, providing medical management, intermittent therapy, community integration and social skills training. The authors reported length of stay data, which ranged from 18 weeks for individuals in the NeuroRehabilitation programs to 68 weeks in the Supported Living programs. Using a test-retest methodology, the study compared MPAI-4 scores at admission and discharge and used a multivariate analysis of variance to evaluate differences between the groups. The results showed significant differences for participants even after 3.3 years of recovery. Although the greatest gains were made by individuals who participated in the NeuroRehabilitation programs, reduced disability was demonstrated by all programs types as measured using the MPAI-4 at discharge (Lewis & Horn, 2013).

A third study also used the MPAI-4 as an outcomes measurement tool to compare progress of a total of 604 individuals with brain injury who participated in four different types of post-hospital rehabilitation brain injury programs, including intensive out-patient and community-based rehabilitation, intensive residential rehabilitation, long-term residential supported living and long-term community-based supported living (Eicher, Murphy, Murphy, & Malec, 2012). The study collected MPAI-4 ratings at two different time periods and examined the changes in scores. The findings indicated that both the intensive residential rehabilitation and intensive out-patient and community based rehabilitation programs resulted

in significant functional improvement across assessments and that in contrast, both the supported living and long-term community based supported living programs demonstrated relatively stable MPAI-4 scores. This is in contrast to Lewis and Horn's (2013) findings that indicated while more intensive rehabilitation provided the largest changes in scores on the MPAI-4, changes for all environments of care within the PHIDBIR-R environments were noted over time. Here, I see the MPAI-4 being used as an outcomes measurement tool across more than one research study and reporting on multi-dimensions of functional progress following brain injury. Yet, another step closer to comprehensive exploration of program improvement, with multiple areas of improvement with functional deficits assessed. The following section delves deeper in to the MPAI-4 as an outcome measurement tool.

Use of the MPAI-4 as an Outcome Measurement Tool

There has been a call for many years for the development of evidence-based practice guidelines for rehabilitation of persons with brain injury and for an increased emphasis for providers to adopt a continuous quality improvement approach for the care which they provide (Cicerone et al., 2005). Malec and Lezak's (2003) MPAI-4 seeks to provide the field of post-hospital services for individuals with brain injury with a sophisticated way in which to use outcome measures to positively impact the process of rehabilitation. The MPAI-4 was designed to assist in the clinical evaluation of people during the post-hospital period following brain injury and to assist in the evaluation of rehabilitation programs designed to serve these people, and to better understand the long-term outcomes of brain injury. The test measures 29 different physical, cognitive, emotional, behavioral and social skills that pose common challenges following brain injury. The MPAI-4 follows the guidelines of the World Health Organization (WHO) distinctions among impairment, activity, and participation (WHO, 1997). Following the WHO guidelines, ratings on each scale item are constructed to indicate whether performance indicates: (0) no problem, (1) mild problem but does not interfere with activities and may use assistive device or medication, (2) mild problem that interferes with activities 5-24% of the time, (3) moderate problem that interferes with activities 25-75% of the time, or (4) severe problem that interferes with activities more than 75% of the time. The MPAI-4 also provides an assessment of the major obstacles to community

integration which individuals may face. The 29 areas of functioning measured are grouped in three categorical sub-scales: “Ability” (sensory, motor and cognitive abilities), “Adjustment” (mood and interpersonal interaction), and “Participation” (social contacts, initiation and money management). The authors contend that these sub-scales were selected on a rational rather than psychometric basis because they are informed by clinical experience and have value in a real-life, clinical setting. Furthermore, while the sub-scales all correlate strongly with the overall MPAI-4 score, they are moderately inter-correlated, suggesting some degree of independence. Periodic re-evaluation of individuals allows for the capturing and reporting of progress and functional improvement (Malec, 2005).

Several studies have documented the internal consistency, reliability, and comparability of the MPAI-4 and sub-scales completed by people with brain injury, family and significant others, and rehabilitation staff (Bohac, Malec, & Moessner, 1997; Malec, 2004; Malec, Kean, Altman, & Swick, 2012; Watford, & Miller, 2011; Zgaljardic et al., 2011). These studies demonstrated that Rasch indicators of internal consistency were entirely within acceptable limits for 3-rater composite full-scale and sub-scale measures, and that these indicators were generally within acceptable limits for measures based on a single rater group. Item agreement was generally acceptable and disagreements suggested various sources of bias for specific rater groups. Conclusions indicate that the MPAI-4 possesses satisfactory internal consistency regardless of rating source. In the clinical setting, assessment of varying individual perspectives and biases may not only best represent outcome as evaluated by all parties involved, but also be essential to developing effective rehabilitation plans (Malec, Moessner, Kragness, & Lezak, 2000). Additionally, an in-press study by Malec, Kean, Altman, and Swick (2012), demonstrates the MPAI-4 to be a valid assessment measurement for individuals diagnosed with the acquired brain injury of cerebral vascular accident, thus extending the umbrella of brain injury to include the use of the MPAI-4 for assessment measurements with those who have experienced brain injury resulting from non-external events as well. The MPAI-4 has demonstrated its comprehensive and over-arching utility as an assessment measurement with individuals post-brain injury.

When reviewing all the studies of PHMDBIR-R outcomes discussed in the paragraphs above as a group, a clear benefit in the value of being able to make comparisons in the evaluation of clinical programs emerges. In addition, there is value in being able to share outcome data with a larger, aggregate database to set standards of care and best practices. Brain injury rehabilitation has become increasingly more complex as individuals are released from acute-care settings faster and in many cases, presenting as more medically complex than in prior years (Kreutzer et al., 2001). Rehabilitation following brain injury continues after the acute hospitalization phase, as a sequelae of functional deficits in varying domains frequently persist, and yet there remains little consensus as to which outcome measure(s) to use and there remains even less collaboration between and amongst post-acute brain injury providers (Krener, 2008). The MPAI-4 represents a tool that could be utilized across PHIDBIR-R program settings. Furthermore, the MPAI-4 can be repeatedly administered so as to compare a client's progress in MPAI-4 score from admission to discharge. Ease of administration and interpretation makes the MPAI-4 a tool that can be implemented in many rehabilitation settings and therefore, an appropriate and effective tool to begin collecting data with for use in the PHIDBIR-R industry (Kreber, 2008).

Though the MPAI-4 has been identified as an effective tool for measuring functional progress across varying domains following brain injury, only one study has sought to examine participants' perspectives on PHIDBIR-R programs, and equally important source of data that needs to be examined when considering program improvement. Using a qualitative design and semi-structured interviews, Gill, Wall and Simpson (2012) interviewed seven participants mid-program and completed the meta-analysis to identify emerging themes in participant responses. The analysis identified four emergent themes that the participants identified as important to the PHIDBIR-R program experience: rebuilding self-belief, reflecting participants' sense of independence and confidence in their ability, recognition of personal identity (including a number of personal traits), acceptance and change, incorporating coming to terms with their brain injury and identifying change, a sense of community atmosphere, and reflecting clients' perception of their own role and relationships with others. While this analysis has begun to help us gain a qualitative understanding of how participants perceived their experience within a residential rehabilitation

unit, it did not tie experiences at this PHIDBIR-R program with functional improvement. This preliminary qualitative exploration also lacks the identification of those constructs that are associated with improvement following brain injury. Indeed, it is not known if those interviewed improved their functioning from their baseline status at admission.

Chapter Summary

Inconsistency marks the determination of efficacy among different PHIDBIR-R programs. Such inconsistency stems from confusion surrounding what efficacy truly means within the PHIDBIR-R industry and consequently, the inconsistency in utilizing a comprehensive outcomes measurement tool that represents the functional ability, adjustment, and participation of individuals who complete PHIDBIR-R programs. Additionally, among research in the PHIDBIR-R programs field, there continues to be poor description of physical environments, program coordination, program components, methods of program delivery, hours of treatment provides per day, duration of programs, disciplines providing treatment, philosophy of care and specific treatments used, staff training and educational preparation, and systems of fidelity checking in each study represented. While in many cases, research indicates that the PHIDBIR-R program produced a change as measured by the outcomes tool, I do not know how such change and improvement was achieved. That is, I do not know which specific variables provided within the PHIDBIR-R program are significantly related to an improved outcomes score, and in effect, which specific variables significantly contribute to the measured functional recovery from brain injury.

While studies to-date have focused on evaluating the efficacy of PHIDBIR-R programs, there has been no systematic study which seeks to determine those specific constructs within a PHIDBIR-R program associated with improvement in functional outcomes. The purpose of the current study is to identify those specific constructs which are significantly related to functional recovery from brain injury. The proposed study seeks to sample the nation's largest provider of PHIDBIR-R programs, inclusive of 135 programs located across twenty states, and identify using the MPAI-4 those participants who have demonstrated the greatest improvements in functional outcomes. From there, the current study aims to determine, as illuminated through a qualitative exploration of individual participant's experiences and

stories, the specific components of their PHIDBIR-R program that contributed to these gains in function following brain injury. The ultimate goal of the current research is to identify those specific program constructs that emerge as common themes recommended for inclusion in PHIDBIR-R programs and contribute to the best evidence-based practice and program improvement within the PHIDBIR-R programs industry.

Chapter III

Methodology

Introduction

The previous chapter's review of literature illuminated some considerations warranting further exploration. First, the systematic identification of individuals who have made improvements from baseline in the range of physical, cognitive, emotional, behavioral, and social deficits that survivors may encounter after brain injury is challenging in the absence of a common, standardized outcomes measurement tool. While nursing homes are federally mandated by the Centers for Medicare and Medicaid Services to use Minimum Data Sets (MDS) for clinical assessment of all residents, there is no standardized outcomes measurement tool used in the systematic evaluation of Post-Hospital Brain Injury Rehabilitation – Residential programs (PHIDBIR-R programs) (CMS, 2013b). While CARF-accredited providers of this level of care are required to use some system of tracking changes in function from admission through to discharge from programming (CARF, 2013), providers do not use the same system of outcomes management or reporting. The utilization of a common outcomes measurement system allows a program to evaluate outcomes by comparison with a standard. In the absence of using the same system, comparison of individual outcomes across all domains of functioning and systematic study of rehabilitation programs is challenging. The absence of an outcomes measurement system, such as MDS, renders the evaluation of these PHIDBIR-R programs through an industry bench-marking system impossible.

Secondly, there is considerable variability in the delivery of CARF-accredited PHIDBIR-R programs. Variations may include differences in environments of care, types of therapies provided, intensity and frequency of therapy provided, location in which therapy is provided and philosophy, minimum training levels of staff and skill level of program direction. For example, environments of care range from a small, three bedroom home set in a community to a large, campus-based environment serving over 100 individuals in various-sized cottages. Therapies may be provided by licensed clinicians or by trained, but unlicensed staff members who deliver life skills training. The frequency of sessions

during which skills are practiced and the number of trials attempted per session may vary. Therapy may be implemented in a more naturalistic community environment or in a structured location utilized only for rehabilitation. Direct care staff may complete one week of orientation training or may participate in a two month training and mentorship program including the completion of various certification programs. Rehabilitation program direction may be provided by a Medical Director who is a Physiatrist or by a licensed Social Worker. The heterogeneity of the programs which self-identify as PHIDBIR-R programs is indeed great.

Thirdly, there exists no systematic research which attempts to identify the elements of a PHIDBIR-R program that correlate with improved function of the frequent residual functional deficits following brain injury. The lack of such a systematic study is described in the previous chapter.

Purpose of the Study

The primary purpose of this mixed methods explanatory design study is to determine and explore the specific constructs of PHIDBIR-R programs that may positively influence gains in function. The investigation involves qualitatively examining the phenomenon of individuals' experiences while participating in a PHIDBIR-R program as part of recovery from brain injury. In order to identify study participants, the study requires the initial quantitative analysis of an assessment which identifies the level of functional improvement that has been demonstrated by individuals participating in this PHIDBIR-R environment. This two- phase explanatory design procedure places priority on the second, qualitative phase of inquiry rather than on the initial quantitative phase. The design is what Creswell and Plano Clark (2011) call the participant-selection variant, which is "used when the researcher is focused on qualitatively examining a phenomenon but needs initial quantitative results to identify and purposefully select the best participants" (p. 86).

Because the study is most interested in identifying and examining those constructs which are related to functional recovery, participants who have demonstrated the greatest improvement in function have been chosen to study. Examination of those who have been least successful may also provide some insight in program constructs, but is beyond the scope of this initial study. Improvement in function was

determined via quantitative analysis using an objective, psychometrically valid outcomes measurement system: the Mayo-Portland Adaptability Inventory-4 (MPAI-4). The quantitative phase was used to select participants for an intensive interviewing phase that then explored in detail the identified participants' and their family members' experience of the rehabilitation process.

A secondary goal of the current research project was to better understand the methodology process itself as specific to the brain injury arena - how qualitative interviews with brain injury survivors and their families treated in a PHIDBIR-R program contribute to a more comprehensive and nuanced insight regarding the survivors' functional improvement. Lastly, the current study aimed to promote action in applying the identified constructs as pillars of inclusion in the PHIDBIR-R programs that the principal investigator develops and manages. Results from this investigation carry important implications for the development and practice of providing Post-Hospital Brain Injury Rehabilitation – Residential programs as a vehicle for optimizing functional improvement following brain injury.

Research Question

The primary questions guiding the current research project were:

1. Who are the individuals who make the greatest gains in function while participating in a Post-Hospital Brain Injury Rehabilitation – Residential program, as measured by the Mayo-Portland Adaptability Inventory-4 from admission to discharge?
2. What are the components of the Post-Hospital Brain Injury Rehabilitation – Residential program that may contribute to these individuals' gains in function?

Mixed Methods Design

There are many crucial variables to consider when choosing a research design – the question guiding the inquiry, the many details of information required to answer the questions and the best strategy for gathering sufficient data (Merriam, 2009). Mixed methods research provides benefits that offset the weaknesses of both quantitative and qualitative research methods as separate entities. Quantitative research denies the direct voice and input of participants and places researchers in the background where

personal biases and background are buried. Qualitative research addresses these deficits. Qualitative research necessarily considers personal interpretations offered by the researcher; however, unlike a quantitative approach, it may prove difficult to extend generalizations involving a larger group of participants due to the lower number of subjects typically included in qualitative inquiry. A mixed methods design provides researchers with tools to capitalize on the strengths of each approach while mitigating the shortcomings of either method (Creswell & Plano Clark, 2011).

To address the current study's research questions, one data source was insufficient to gather both the type and depth of information required. First, to identify those participants from different PHIDBIR-R programs who have demonstrated the greatest improvement in function, this study examined a sufficiently large number of people, ideally more than 500, and assess their responses to a set of outcome variables. This purposive sampling identification of individuals is best achieved by using quantitative methodology and analysis of data. However, the results of this quantitative analysis will only provide one piece of the puzzle and leaves the question lacking deeper understanding of the research problem to support the numbers - the voice of those at the core of the question warrants critical exploration. A second, constructivist method of data collection and analysis provided enhanced and crucial detail to help explain the first database. The overall research objective was best addressed with multiple phases. Creswell and Plano Clark (2011) indicate that this type of research problem is suited for mixed methods.

Nested within a pragmatic paradigm of research, the design was developed to produce a methodological structure capable of satisfying breadth and depth of a study's aims. The positioning of a pragmatic world view was chosen as a utilitarian approach to data collection will be employed, which acknowledged the multiple perspectives of the nature of each subject's constructed reality. To best address the research question of the current study, a two-phase mixed methods approach was used (see Table 2). Phase 1 will used a participant selection variant within an explanatory design, as described by Creswell and Plano Clark (2011), in which priority will be placed on the second, qualitative phase, rather than the initial quantitative phase. The research required initial quantitative results to identify and

mindfully select participants. The broad quantitative data retrieved within Phase 1 orientated the focus of Phase 2.

Table 2

Study Phases 1 and 2

Phase	Strategy	Sample	Goal	Analysis
1	Quantative MPAI-4 data analysis: admission scores compared to discharge scores	All program completers from all sites (Oct 1, 2012 – Sept 30, 2013)	Identify 50 participants with greatest overall reduction in T-scores (indicates reduction in disability)	Serial assessment using repeated measures design
2	Qualitative data collection: semi-structured interviews	10-50 participants with greatest functional gains and their family members	Identify emerging themes of the rehab program associated with functional improvement	Identification of common and individual themes/constructs

Procedures

Phase 1: participant identification. The overarching aim of Phase 1 of the current study was to identify at least fifty participants who had participated in rehabilitation and who had demonstrated the greatest improvement from baseline in an aggregate score of the most frequent areas of residual changes (or sequelae) associated with brain injury. These sequelae included residual challenges that represent the range of physical, cognitive, emotional, behavioral and social problems often encountered following brain injury as measured by the MAPI-4. Some examples of these sequelae include changes in motor speech, balance, attention/concentration, verbal and nonverbal communication, memory, irritability, social interaction, self-awareness, initiation of activity, self-care, drug and alcohol use, employment status, and ability to manage finances, among many more specific skills.

To control for the different patterns of recovery that different types of brain injuries may follow (Lewis & Horn, 2013), it was critical to the current study that all participants be diagnosed with traumatic brain injury. For example, individuals diagnosed with stroke and anoxic brain injury will not be included in the study. The narrowing of the brain injury diagnosis to traumatic brain injury only will provide a better representative sample of one type of program participant. As indicated in previous chapters, there is confusion surrounding the term acquired brain injury. This study will use the Brain Injury Association of America (2012) and Brain Injury Alliance of New Jersey (2012) definition of Traumatic Brain Injury as provided in Chapter I. Additional inclusion criteria required that each participant:

1. Was treated at any one of the NeuroRehabilitation PHIDBIR-R environments of care operated by (name of national company). The company has agreed to allow their outcomes data to be utilized for participant selection purposes. (It is noted that the company operates several different programs inclusive of NeuroRehabilitation programs; NeuroBehavioral programs; Supported Living Programs; Transitional Programs; Home and Community Programs; Out Patient Programs; Day Treatment Programs and Respite Care).
2. Was aged 18 to 70.

Persons who do not meet the above criteria were excluded from the study. These criteria were selected for several reasons worth highlighting. Given the overall aim of the study was to determine variables that are significantly related to recovery from brain injury, it was important to include participants carrying a specific diagnosis of brain injury.

While all participants in the study will have a diagnosis of brain injury, it was likely that the individuals were be heterogeneous across many other demographic categories. This study did not seek to identify correlations between functional improvement and demographic factors. However, it is important to note that three demographic considerations in addition to age, gender, handedness, education level, first language, and previous brain injury are likely to be disparate and potential confabulating details.

Demographic details include:

1. Time from injury. While some individuals admit to a PHIDBIR-R program immediately following medical stabilization in an acute hospital environment, others access PHIDBIR-R programs several years following injury. As discussed in the previous chapter, early access to rehabilitation has been correlated with improved outcome.
2. Severity of injury. Brain injury can be categorized into three different levels that represent the severity of the brain injury *at the time of the injury*. Table 3 indicates the criteria for inclusion in these three categories. As noted in the previous chapter, the more severe an injury at the time of injury, the more sequelae of residual symptoms are expected. Individuals treated at the PHIDBIR-R programs included in this study tend to have sustained moderate to severe injury.
3. Time spent at the PHIDBIR-R program. Inclusion criteria has not been set to include a minimum or maximum number of months. It is likely that there will be differences in lengths of stays.

These differences in demographic information were reported.

Table 3

Severity of Brain Injury Definitions

Criteria	Mild Brain Injury	Moderate Brain Injury	Severe Brain Injury
Injury Experience	No loss of consciousness or loss of consciousness for less than 30 minutes.	Coma more than 20-30 minutes, but less than 24 hours.	Coma longer than 24 hours, often lasting days or weeks.
Glasgow Coma Scale	13-15	9-12	3-8
Post Traumatic Experiences	No EEG, CAT, or MRI scans; amnesia, less than 24 hours; signs of temporary or permanently altered mental or neurological state; post-concussion symptoms.	EEG, CAT, or MRI scans show skull fractures with brain bruising, bleeding possible; long term problems in one or more areas of life (i.e. home, work, community).	EEG, CAT or MRI scans show brain bruising, bleeding; Long term impairments in one or more areas of life (i.e. home, work, community).

Note. Adapted from the “Certification Exam Preparation Course Work Book” by the American Academy of Brain Injury Specialists, 2007, p. 67

Convenience sampling involves a sample selected based on dimensions of convenience for the researcher such as viability, location, or accessibility. Participant selection based solely on convenience sampling may not prove credible and may not produce information-rich cases (Merriam, 2009). The researcher chose to use convenience sampling to select participants served only by one national company, providing 127 different environments of rehabilitation across 22 states because:

1. This is the largest PHIDBIR-R program provider in the world and will provide the greatest variability in program constructs.
2. The environments of care are spread across 22 states, again providing the greatest variability in program constructs.

3. The company uses one psychometrically valid outcomes measurement system across all of its programs, allowing for accurate and consistent comparison of outcomes of participants served in different environments. This measurement is the Mayo-Portland Adaptability Inventory-4 (MPAI-4) and is discussed in greater detail below.
4. Per company policy, the reliability of demographic data collection for each participant of a PHIDBIR-R program is high.
5. The company has agreed that the current study may use these data for the purposes of participation selection.
6. The principle investigator works for the company as the Vice President of Development, which lends access to the “gatekeepers” of these data.

Adults aged 18 to 70 only were included in this study as all states’ licensing of PHIDBIR-R programs require separate environments of care for children (aged 18 and younger) and adults. Children were excluded as participants to avoid the introduction of a confounding variable (a children’s programming environment).

Instrument. The Mayo-Portland Adaptability Inventory-4 (MPAI-4) was selected as the outcomes measurement instrument used for this phase, which entails a repeated-measures design. The time period during which individuals were sampled include one year of data collection from October 1, 2012 through September 30, 2013. The MPAI-4 is a measure designed to provide outcomes for post-acute care with neurological rehabilitation efforts. The national rehabilitation company which agreed to provide outcomes data for this study uses the MPAI-4 to provide outcome data for their programs across the country. The company implemented systematic use of this measure company-wide in October of 2010 and utilizes this measure as a way to reliably and consistently measure outcomes that could contribute to a national data base and provide comparisons with other facilities around the country. This measure has been assessed to be a reliable tool for assessing individuals with brain injury (Malec et al., 2003; Malec, 2004; Malec, 2005; Zgaljardic et al., 2011; Eicher et al., 2012).

The MPAI-4 and its three sub-scales offer measures with extensively developed and well-documented psychometric properties, as discussed in the previous chapter. The test's three subscales were identified as corresponding to rational grouping for three categories: Ability (e.g. sensory, motor, and cognitive abilities); Adjustment (e.g. mood, interpersonal interactions) and Participation (e.g., social contacts, initiation, money management). The MPAI-4 provides the rehabilitation professional or other clinician with a brief and reliable means of assessing functioning in each of these three major domains to help target areas for intervention and assess progress. The MPAI-4 rating system provides consistency of rating with high inter-rater reliability for accurate assessments of function across disciplines and therapists. The rating system is illustrated as follows:

- 0 = No Impairment
- 1 = Mild problem without interference in function
- 2 = Mild problem interferes 5-24%
- 3 = Moderate problem interferes 25-75%
- 4 = Severe problem interferes > 75%

A system of MPAI -4 data collection is used throughout the programs in the facilities involved in the study, inclusive of twenty two states operated by one national PHIDBR-R provider who participated in this study. The protocol developed and implemented for MPAI data collection required the development of a password protected database (an Access software program was used to create the database) in which to store all demographic information and all MPAI- 4 serial measurements. Database access is restricted to only three individuals. All clinical, case management and management staff at each of the PHIDBR-R provider's sites are trained via webinar using audio and Power Point slides which describe and instruct staff on the MAPI-4 rating protocol. Details about the five point rating scale and each of the 29 items' measurements are discussed in detail. The webinar based training is offered once monthly and all staff identified as raters (clinicians, case managers, and managers) must participate once yearly in the training and successfully complete a multiple choice, fill in the blank and True/False written posttest earning a score of 80% or higher to be approved ad eligible to rate a program participant using

the MPAI-4. Practice ratings are completed and inter-rater reliability is established by groups of staff who are participate in a training by comparing and discussing ratings on the same individual. (It is noted that the MPAI-4 has a very high reliability as discussed in previous chapters with Pearson Reliability studies for the MPAI-4 ranging from 0.78 to 0.88 (Malec & Lezak, 2008). Each participant in every program operated by this PHIDBR-R provider is rated within three days of admission to a PHIDBR-R program using the MPAI-4's 29 items. Completed ratings are sent to one quality assurance analyst who converts all raw scores to T-scores. The results are reviewed by one PhD level psychologist to determine if there are any surprising scores or scores which require immediate clinical response or further explanation. Once this is satisfied, the raw scores for each of the 29 items and the three subscales (Ability, Adjustment, and Participation Indices) are entered into the database corresponding to each individuals' demographic information. This provides an Admission Score for each individual. Standardized T-scores for each of the subscales and for the total score are also entered into the database. Upon discharge, each of the individuals is again rated via the MPAI-4 using the same protocol. Although not germane to this study, the participation subscale portion of the MPAI-4 is repeated three and six months following discharge from the program) with this second set of scores for each of the 29 items and the three subscales (Ability, Adjustment, and Participation Indices) entered into the database management system This provides a Discharge Score for each individual. This system of reliable data collection, organization and storage has created a very large database with scores from well over 1000 individuals.

For the purposes of the current study, a *Change Score* was determined for each individual who met the selection criteria. The *Change Score* was determined by subtracting the post-test total standardized score, (as gathered at discharge from the PHIDBIR-R program) from the pre-test total standardized score (as gathered at admission to the PHIDBIR-R program) for all participants during the identified twelve-month period. These *Change Scores* was ranked from highest to lowest value. This ranking ordered participants with the greatest change in score to those participants with the lowest change in score. Those fifty seven participants with the highest ranking scores were, together with their family members (if applicable), invited to participate in Phase 2 of the study. All participants and family

members were identified as possible participants in Phase 2 of the study although not all potential participants were expected to participate in Phase 2 of the study. Oversampling was intentional as it was anticipated that some participants identified in Phase 1 may decline to participate and that not all would be required to complete Phase 2. The decision to activate a participant for Phase 2 of the study is discussed below and included in the discussion concerning data saturation.

The national company which operates the 127 PHIDBIR-R programs noted earlier in this chapter was provided with a proposal to use these data for the purposes of identifying program participants for the Phase 2 of the study. The researcher submitted a request to the company's institutional review board detailing the study's proposal. A Memorandum of Understanding was developed to authorize use of the data. It is noted that the investigator is an employee of this national company and that all data used and generated was likely to be viewed as a component of the quality assurance plan for the company.

Demographic information including age, sex, number of months post-injury, number of days of in-patient treatment at PHIDBIR-R program and type of brain injury was collected from an existing database and was reported for each of the individuals selected in Phase 1. Each participant was assigned a gender neutral name and all participants were identified only by the gender neutral name. A spreadsheet containing the pairing of a participant's demographic information and assigned research name was stored in one location, locked filing cabinet to which only the current researcher as the key.

Phase 2: post-hospital brain injury rehabilitation – residential program experience. Phase 1 of the research study identified those participants who made the highest levels of improvement from baseline during their rehabilitation program. The main objective of Phase 2 was to explore specific variables experienced at the PHIDBIR-R programs that contributed significantly to participant success. It was expected that participants have spent varying amounts of time at the PHIDBIR-R programs. This phase aimed to determine precise activities, environmental details, specific supports, or services during this time spent at the PHIDBIR-R programs that are viewed by program participants and their family members as helpful in achieving success. To achieve this in-depth exploration, the research used a constructivist qualitative approach to inquiry.

The study could not aim to observe a single reality because such singularity in experience does not exist. This scientific inquiry did, however, approach the research question with the notion that as individuals reflect upon their experiences, they are constructing their individual realities. Supporters of the constructivist concept contend that it is impossible to know an individual's reality by taking an objective position. Charmez (2006) well-articulated that, "Constructivist inquiry starts with experience and asks how members construct it. To the best of their ability, constructivists enter the phenomenon, gain multiple views of it and locate it in its web of connections and constraints" (p. 187). In this way, this study aimed to interpret the phenomenon (rehabilitation as created and provided at the PHIDBIR-R programs) through understanding the many, and perhaps varied, realities of those who have successfully participated in the phenomenon.

Phase 2 of the study adopted an inductive methodology that began with participants' views and explored emerging patterns, theories and potential generalizations through an open-ended interviewing technique (Creswell & Plano Clark, 2011; Merriam, 2009). Qualitative studies search for recurring patterns in the collected data to understand how individuals interpret their experiences and make sense of their experiences (Merriam, 2009). These data were expressed as words and actions, and were collected through observations, written documents and interviews. When the researcher wishes to learn about past experiences or how people interpret these experiences and make sense of their worlds, interviewing provides the best methodological fit (Merriam, 2009). Interviews allowed the researcher to glimpse into those variables that could not be observed as an outsider, lending voice to their experiences of the rehabilitation process and their evaluative perspectives on those constructs of the program that they determined as significant in their improvement. The interview protocol is described later in this chapter.

For the purposes of this research, those variables which participants identified as significant components of the PHIDBIR-R programs (inclusive of specific activities, elements, attitudes, approaches, services, supports, requirements, environmental details, et cetera) were referred to as *constructs*. Each PHIDBIR-R program has created, intentionally or unintentionally, the constructs of its program, and has woven them into the rehabilitation participants' experience. Phase 2 captured and described the

experience of the rehabilitation constructs. This has also been useful in current program evaluation and validation as core constructs related to functional recovery from brain injury were identified and are in use.

Establishing Initial Contact with Participants

The study's investigator contacted the individuals and respective family members of those individuals who achieved the highest change score on the rank order of MPAI-4 in Phase 1 of the study. The researcher introduced herself and explained that was calling from (name of the national company), She provided a summary of the research, the process of data collection and the James Madison University Institutional Review Board approval. She used the following introduction template by reading the following prompt:

Hello, my name is Victoria Harding, and I am calling from (name of national company). I regularly review outcomes of program participants and you have been identified as someone who made above average gains in your rehabilitation. I am interested in learning about your rehabilitation experience and what was most helpful. I am doing a research study to help identify those things that you found helpful so that I can be sure to include those things in all of our programs and help other people who have brain injuries achieve success. The research is part of a study that I am doing in partial fulfillment of a Ph.D. degree and has been approved by James Madison University's Institutional Review Board. The study is not expected to cause you discomfort and requires one face-to-face interview in which I will ask you about your rehabilitation experience at (name of national company). In a separate interview, I will also ask your family member, or the person who you feel has provided you with the greatest support throughout your rehabilitation journey about how his/her experiences with (name of national company) and what they think was most helpful to you. Is this something that you may be willing to participate in?

If the individual has a guardian, then the guardian was contacted initially, rather than the individual who had participated in the rehabilitation program. If the contacted individual(s) agreed to participate in the interview process, a time and place was arranged that was convenient to meet, which was in all cases, the

individual's home. If either the guardian, or the individual who was served in the PHIDBIR-R program did not wish to participate, then the interview phase was of course not initiated.

Data Collection Protocol

A person-to-person interview focused on generating data on the PHIDBIR-R program experiences guided the collection. The interviews took place in a private setting within a home. For each individual selected to participate in Phase 2 of the study, both the individual and willing family members participated in a semi-structured interview. Initially, there it was determined that family members would be interviewed separately from participants so that all voices were captured and input was maximized from varying perspectives and stakeholders. Interviewing the participant and the family member separately may have prevented the introduction of potential family dynamics and family role variables that may later confound the analysis. However, in every case, both the individual with the brain injury and the family member requested that they be interviewed simultaneously. Interviews were conducted within 30 to 80 minutes and were recorded via digital recording. Audio recordings were transcribed verbatim for the analysis and were stored on both a password-protected computer and a memory stick stored in a locked filing cabinet to which only the investigator maintained access.

For the purposes of determining how many interviews were to be completed, the process of sampling saturation as described by Richards (2005) was used. When the catalogue of ideas began to shrink, when primary and non-essential constructs emerged and when the researcher was continuously merging categories and deleting irrelevancies, data collection ceased. Charmaz (2006) well describes categories as being saturated when gathering fresh data no longer produces new insights. It was estimated that 10 to 25 interviews of former participants and family members would achieve this saturation.

Interview Format

The investigation used a semi-structured, open-ended interview for data collection. Specific information was elicited from responders, while the ordering of the data and the data elicited varied. This format was chosen to allow for flexibility in elucidating the feelings and opinions of responders while permitting time to be spent identifying and describing those constructs which the responders self-identify

as significant. The format easily allowed for review by anyone who was interested in this study. Open-ended questions were designed to yield descriptive data and stories about the phenomena of the PHIDBIR-R program experience. If responders had difficulty in identifying specific program constructs, additional probing questions were asked. Patton (2002) outlined different types of questions were used in an interview. Questions posed in the study's interviews were consistent with Patton's *experience and behavior questions* in that the respondent is asked about behaviors, actions and activities. Some questions also fell into Patton's category of *sensory questions*, aimed at eliciting more specific data about what was seen, heard, touched and experienced at the program.

Interview Protocol

Before beginning the interview, a summary of the research study's aims and restatement of James Madison University Institutional Review Board approval was restated. The informed consent was reviewed and the procedures for recording and transcribing the interview were described along with the member-checking process. A copy of the signed informed consent was provided to each participant. A number and a gender neutral pseudonym was assigned to each of the interviewees that was used to identify each participant in the recording and transcription. As noted previously, this researcher is an employee of the national company which operates the identified participants' PHIDBIR-R programs and as such, was viewed as an extension of the quality assurance and quality improvement efforts with which the participants and family members were familiar. The investigator explained that this is in partial fulfillment of the requirements for this researcher's doctor of philosophy degree. Next, the researcher read the following prompt:

I am interested in learning about your (your loved one's) experience at (name of national company). Thinking just about this program in which you (your loved one) participated as part of your brain injury rehabilitation, I am going to ask you some questions. There is no right or wrong answer. You can stop the interview at any time without any type of penalty. This is entirely voluntary and you will not be paid for your time. Do you feel ready to begin?

The interview process then began using the questions below as a guide. The exact sequence and word order of the questions varied as recommended by Charmaz's (2009) strategies for effective interviewing, as it is recognized that interviewees may wish to expand upon a response or a theme. The interview style should accommodate this. Questions that will form the basis of the semi-structured qualitative interview include:

1. Tell me about your (your loved one's) rehabilitation experience at _____.
2. Tell me about a typical day at the program.
3. What was it like for you (your loved one) when you participated in the program?
4. What do you think it was about the program that helped you (your loved one) make such a good recovery?

Probing questions

5. Tell me about a time when you (your loved one) really felt like you had made some progress in your rehab.
6. Give me an example of how you (your loved one) improved.
7. Tell me more about (xxx)
8. Which of the day-to-day activities were most helpful?
9. Think about staff members who helped you (your loved one). What activities or approaches did they use that were helpful?
10. Think about the buildings and the way the rooms and the activities in the rooms were set up. What was helpful?
11. Think about the community where the program is located. What was helpful?
12. Think about the other participants who were there at the program. How did they affect your experience?

13. Think about when in your (your loved one's) recovery that you entered the rehab program.

Do you think that was the right time in your recovery to go or would it have been more helpful to go at a different time?

14. What do you think it was that you (your loved one) did that helped you (him/her) improve?

15. What is or what is it about (your loved one) that helped you (him/her) improve?

16. What did your family (you) do that was helpful?

17. What else was helpful?

18. Is there anything else that you would like to add?

Credibility Procedures

To affect the discipline, a research study must stand up to the scrutiny that readers inevitably bring to its evaluation. Lincoln and Guba (2000) refer to a study's being "sufficiently authentic," in that through the demonstrated rigor of its inquiry, its readers can be trusted upon to act on its implication. Regardless of the methodology selected, validity and reliability are concerns that must guide data collection, analysis, interpretation and reporting. In the psychometrics, validity of measurement is considered to be the degree to which the tool measures what it claims to measure. This study must ensure that in using the interview process, it is truly harvesting illumination of those program constructs that program participants and family members associate with functional improvement. In qualitative inquiry, it is accepted that validity is relative and is assessed in relationship with the purpose and circumstance of the research (Maxwell, 2005). The interview process used in the current study will investigate participants' construction of reality - how they understand the world and their roads to recovery. Truly, this more closely probes reality than if a data collection instrument were to be inserted between researcher and participant. The interview is less abstract than other instruments such as a survey or rating scale (Merriam, 2009). The participants to be interviewed have demonstrated the highest levels of functional improvement from baseline, thus supporting that their descriptions of the rehabilitation are tied to specific, measured improvement in outcomes.

The study must demonstrate reliability in its consistency of measurement. Since a measure can be determined to have high reliability if it produces similar results under consistent conditions, this study's methodology must ensure that repetition will produce similar results. The following strategies for promoting validity and reliability were accessed during this study: process notes, member checking, peer review, and memo writing.

Process notes. To consistently position the researcher and monitor potential personal biases, assumptions and perspectives, Merriam's (2009) notion of reflexivity was implemented by deliberately examining the researcher's position throughout the data collection process. Process notes that required recording of the researcher's thoughts, feelings, cultural considerations, biases, impressions and follow-up were employed. As a cue to record these at the conclusion of each interview, a "Progress Note Cuing Form" was created. The form prompted required entry under the headings "My Initial Thoughts," "Personal Feelings I Recognized During the Interview," "Cultural Considerations During the Interview," "My Biases," "Overall Impressions," and "Follow Up Required." Richards (2005) indicates that the most constructive means of separating one's prior knowledge and preconceptions is to document them, and for the current study, this was accomplished through the Process Notes protocol.

Member checking. In a conscious attempt to avoid misinterpretation of meaning of what participants divulge in their interviews, a respondent validation of *member checking*, as decided by Lyn Richards (2005) was used. The investigator solicited feedback from at least 1 of three of the people interviewed about emergent findings. That is, preliminary analysis was taken back to some of the participants and they were asked if the themes resonate with their experiences. This member check in was completed at the initial meeting place for each participant and was not compensated. The format of member check in follow up questions followed the outline below:

Thank you for taking time out of your day to meet with me again. I was looking at what I talked about last time. After I listened again to our discussion, I started to boil down it down to what I think I heard you say. I heard you say that you really though some things helped you to improve. I'd like to talk with you about these things and make sure that I understood you correctly. Is that

alright? There is no right or wrong answer. I can stop this review at any time without any type of penalty. This is entirely voluntary and you will not be paid for your time. Do you feel ready to begin?

The themes of the constructs were then listed and after each, the interviewer asked “Is that what you wanted to identify as something that helped you?”. At the conclusion the question: “Is there anything else?” was posed. If the emergent findings were interpreted correctly, participants were able to recognize their experiences or suggest some balancing, correcting or tuning to improve interpretation. Member Check in comments and actions taken are reported in Chapter IV.

Peer review. While the opportunity to add credibility to the research through a process of examination is built in to the dissertation committee process, this research project also utilized a peer review process. Colleagues familiar with the research were asked to scan the raw data of the interview and assess if the findings appeared plausible based on the data. Prior to beginning the peer review process, a period for discussion about the process was provided. Both colleagues were be provided with guidelines about the peer review process as outlined in Lincoln and Guba (1985) which indicate the role of the peer reviewer as a critical examiner who may play devil’s advocate and encourage the researcher to question findings in the data. The peer reviewers selected for the current study both held advanced degrees and worked with individuals who had sustained brain injury more than two years.

Memo writing. Richards (2005) describes memos as “the place where the project grows, as your ideas become more complex and, later, more confident” (p. 74). Memos produced as part of the research represented personal, informal records utilized to track and organize ideas, musings, speculations and hunches in an effort to try out ideas and themes as initial thoughts. The study relied upon Richard’s recommended memo writing in which the researcher creates documents as a means of remaining actively engaged in data collection and considers such record keeping about thoughts on method (how the data have been created), emerging ideas (interesting themes or concepts that become apparent) and ideas for future research. To compose each memo, Richard’s five-step process was used:

1. Skim read, then read very thoroughly

2. Record everything interesting
3. When something interesting is found, ask myself why it is interesting and record the reason
4. Focus on passages and remind myself to compare them with others
5. Ask myself, “why am I interested in that?” and record the your answer

Memos will serve to form the rudimentary stages of analysis.

Qualifications and Involvement of Researcher

In positioning this study within a constructivist worldview, it is expected that researchers openly discuss their biases and interpretations. It is important for the researcher to position herself in relation to the participants of the study and to discuss past experiences, biases and views that will affect the interpretations of data collected (Creswell, 2007). This reflexive reporting of predisposition allows the qualitative researcher to demonstrate that her findings are honest, meaningful, credible and empirically supported (Patton, 2002). Appendix E represents the position the investigator brings to the current research study, in an effort to illuminate her background and perspective.

Data Analysis Procedures

Data analysis is the process used to answer a research question. Merriam (2009) explains data analysis as a “complex process that involves moving back and forth between inductive and deductive reasoning, between description and interpretation. These meanings or understandings or insights constitute the findings of a study” (p. 176).

In this study, data collection and analysis will proceed simultaneously and I will examine each interview as it is generated. I will begin by identifying segments of the dataset that relate to my research question. A single segment, or unit of data, involves any meaningful piece of information which reveals information that is meaningful to the study and that can stand on its own - it requires no additional information to comprehend its meaning (Lincoln & Guba, 1985). My task will be to compare one unit of information with the next throughout the dataset in an attempt to find recurring units. In this way, I will break down information into units and then assign these units categories or classes while looking for common and novel emergent themes.

Coding data. The term “coding” is used extensively in qualitative analysis. Charmaz (2009) suggests that coding is essentially nothing more than assigning a short-hand designation to data so that specific pieces may be retrieved. Each interview was coded with a gender-neutral pseudonym and case number to allow for easy retrieval of transcripts.

The coding process was initiated with open coding by identifying any segment of the data that responded to the study question and pulling out specific words and phrases. Corbin and Strauss (2007) term this method “axial coding,” which facilitates the initial construction of emerging categories. Categories were determined as those containing numerous individual examples of units, with the units acting as supporting incidents of the emerging category from which the category was constructed and named. In this way, categories were formed that demonstrate a recurring pattern within the data in order to identify common themes that occurred across the experiences of all the participants interviewed. Therefore, construction of categories was highly inductive in that the exploration for common elements produced a category. In turn, it was then deductive in that a category was created, and a researcher searched to determine if it existed elsewhere in the data. To facilitate coding, a software package, NVivo 10®, was utilized that was designed specifically for analyzing qualitative data. The investigator gained experience using an earlier version of NVivo, and began working with NVivo 10 to gain practice and increase comfort and confidence in the use of this updated version.

Coding of the collected data required great care, time and openness. Qualitative data analysis required that the researcher stop and ask analytic questions of the data gathered. The questions asked only furthered understanding of the research topic, but also guided subsequent data collection toward the themes actively being defined during the process of data coding. The data analysis in this phase adhered to Charmaz’s (2006) framework of coding in grounded theory which commences with open coding and progresses to a focused and integrative approach. Charmaz’s description of grounded theory coding is defined as a process that “generates the bones of your analysis” and builds a framework through theoretical integration, which “will assemble these bones into a working skeleton.” (p. 45). It is this

method by which interpretation of the data gathered by interview in the current study was given meaning and relevance.

In keeping with Charmaz's recommended approach, the first analytic step of coding represented defining what was the essence of the data. Every segment of data was be categorized with a short name that both summarizes and accounts for each piece of the data. That is, each line of data from the interviews was mapped to emergent categories. Line-by-line coding was used to take segments of data apart and name each with a concise, descriptive term. A line-by-line system was chosen to alleviate any tendency by the coder to become and remain immersed in the interviewee's world view and lose opportunity to reveal small segments of important information. During this initial stage of coding, each concise term became a code - a theoretical category that the statement in the data indicates. Thus, the codes during this initial phase closely imitated to the data. The short names chosen for the codes reflected action and were derived from words contained in the data. These initial codes then served as comparative, though provisional categories grounded in the data. For each completed and transcribed interview, initial coding was completed soon after the interview. The research initiated the analysis phase of initial coding that occurred throughout the process/phase of gathering of more data through additional interviews.

It is important to consider that over time and as more interviews are completed, there was a tendency to change initial coding and potentially affect reliability. Reliability represents consistency over time and all inconsistencies over time were discovered and reported. The current study utilized a consistency-checking method as recommended by Richards (2005) which requires two coding runs of the same transcript. Following the fifth transcript coding and each fifth transcript following, the same researcher re-coded a fresh, un-coded version of a transcript that had been coded earlier in order to compare original codes with the second version in an effort to discover if coding differences are present. This consistency-checking is reported.

Following this initial phase of data coding, analysis used a focused, selective phase of coding that identified the most significant, or frequent, codes to organize the data and begin to identify common

themes. It is during this subsequent phase that codes and data were compared with each other. As described by Charmaz (2006), this phase conceptualized how the substantive codes may relate to each other as potential hypothesis which was then integrated into a theory illuminating which constructs of a PHIDBIR-R program are significantly related to functional recovery from brain injury. The substantive codes helped to move the analytic story towards the direction of a theoretical model.

Sorting, diagramming and integrating data. Throughout a process of sorting, diagramming and integrating categories, robust categories and pervasive analysis were developed. The data sorting began with coding into categories. Throughout the coding process, the investigator produced memos on each category to prompt continuous analysis and record emergent thoughts. Once categories were established, they were sorted. Charmaz (2006) describes the process of sorting as one that provides a means of creating and refining theoretical links and category integration. The act of sorting encourages the comparison of categories at an abstract level. Charmaz's recommended system, which was implemented for the current study, for sorting, comparing and integrating memos includes sorting memos by the title of each category and comparing categories. By sorting, Charmaz contends that one can see relationships between categories more clearly. The relationships between these categories form an outline of a model.

Diagrams serve as the visual representation of categories and their relationships. Analysis of data collected includes use of diagramming to represent the relative power and direction of categories and the connections between them. This process aids in the development of an integrated model of constructs that relate to functional recovery from brain injury, as it sharpens the relationships among categories.

What will all this data gathering and analysis create? Richards (2005), in her practical suggestions for dealing with qualitative data, asks a simple but important question: "What might your possible outcome look like?" Qualitative research brings together ideas that emerge from data to answer questions. In the current research question, the researcher sought synthesis of data that produce core themes or constructs. From this qualitative research, the intention was to produce a useful outcome, rather than to create a grand theory. The ultimate goal of the current research was to create best practice in PHIDBIR-R programs. To do this, the researcher described essential elements of program inclusion

that best fit to the data collected from those participants who have been most successful in their rehabilitation outcomes. This highlights which constructs should be included in the development of new PHIDBIR-R program as well as added to currently running programs.

Identifying significant constructs will serve to educate staff, funders, families, and participants about what those who were most successful in decreasing their disability following brain injury viewed as being the most helpful. To achieve this, the goal was to determine specific constructs. For example, it is not enough to state that the staff are encouraging. How was that encouragement expressed? How did the staff behave? Specifically, what did the staff do to be encouraging? If a specific modality of treatment (for example, cognitive exercises) was most helpful, what about those exercises helped? Which exercises?

The study sought synthesis – a distillation of the complexity of each individual’s story in to those elements that are central or crucial. The outcome of the research is be a model where the interplay of constructs provided by a PHIDBIR-R program are identified and explained. However, in approaching this research, the investigator remained open to the possibility that difference itself may emerge as the big story of this research - that the constructs may be about individual differences, discovered patterns or contrasts, and that this information could prove useful to PHIDBIR-R program development as well.

It was beyond the scope of this study at this time to seek validation of participants’ and respective family members’ identified constructs with objectively measured improvement in function. Inclusion of construct validation would necessitate a much tighter methodology of categorical presentation and discussion as opposed to more free and robust responses targeted in Phase 2 of this study. A follow-up study may address this path/variable modeling in the future.

Chapter Summary

The purpose of the current research was to identify the constructs of a PHIDBIR-R that are significantly related to functional recovery from brain injury. In order to identify those individuals who have been most successful in their functional recovery, quantitative analysis was used via repeated-measures change scores from the Mayo-Portland Adaptability Inventory-4. Qualitative analysis, inclusive

of participant and family member interviews, was used to generate data about the details of individual PHIDBIR-R program constructs that were associated with functional improvement from baseline following the brain injury. The goal of the current research was to determine best practice guidelines for PHIDBIR-R programs and include significant constructs as experiences across participants and revealed by the data analysis in all rehabilitative programs. The outcome of this research represents a model that describes the constructs, their density, scope, direction and relationship to one another. This model is one that readers may place confidence in as being derived from sound methodology and technique that demonstrates sufficient rigor of analysis. The methods as described above are well –founded in research as support for instilling reader confidence.

CHAPTER IV

Results

Introduction

Chapter III provided a brief introduction to mixed methods research and a detailed description of the methodology used in the current study. The primary questions guiding the inquiry were: 1) Who are the individuals who make the greatest gains in function while participating in a Post-Hospital Brain Injury Rehabilitation – Residential program (PHIDBIR- R), as measured by the Mayo-Portland Adaptability Inventory-4 from admission to discharge and 2) What are the components of the Post-Hospital Brain Injury Rehabilitation – Residential program that may contribute to these individuals' gains in function? This mixed methods explanatory design study sought to determine and explore the specific constructs of PHIDBIR-R programs that may positively influence gains in function. There were two additional aims of the investigation: 1) to better understand the methodology process itself as specific to the brain injury arena (that is, how qualitative interviews with brain injury survivors and their families treated in a PHIDBIR-R program contribute to a more comprehensive and nuanced insight regarding the survivors' functional improvement) and 2) to promote action in applying the identified constructs as pillars of inclusion in the PHIDBIR-R programs.

Phase 1: Identification of Subjects Via Determining Greatest Change Scores

The overarching aim of Phase 1 of the current study was to identify at least 25 participants who have partaken in rehabilitation and who have demonstrated the greatest improvement from baseline in an aggregate score of the most frequent areas of residual changes (or sequelae) associated with brain injury. Previous chapters have described the choice rationale for use of The Mayo Portland Adaptability Inventory-4 (MPAI-4) (Malec & Lezak, 2008) as the optimal tool chosen for this study to measure change in function due to its ability to provide a comprehensive evaluation of the cognitive, physical, and behavioral sequelae following neurological injury. The MPAI-4 consists of 29 items rated from 0 to 4 on a 5-point scale, where 0 represents no limitations and 4 represents a severe problem interfering with

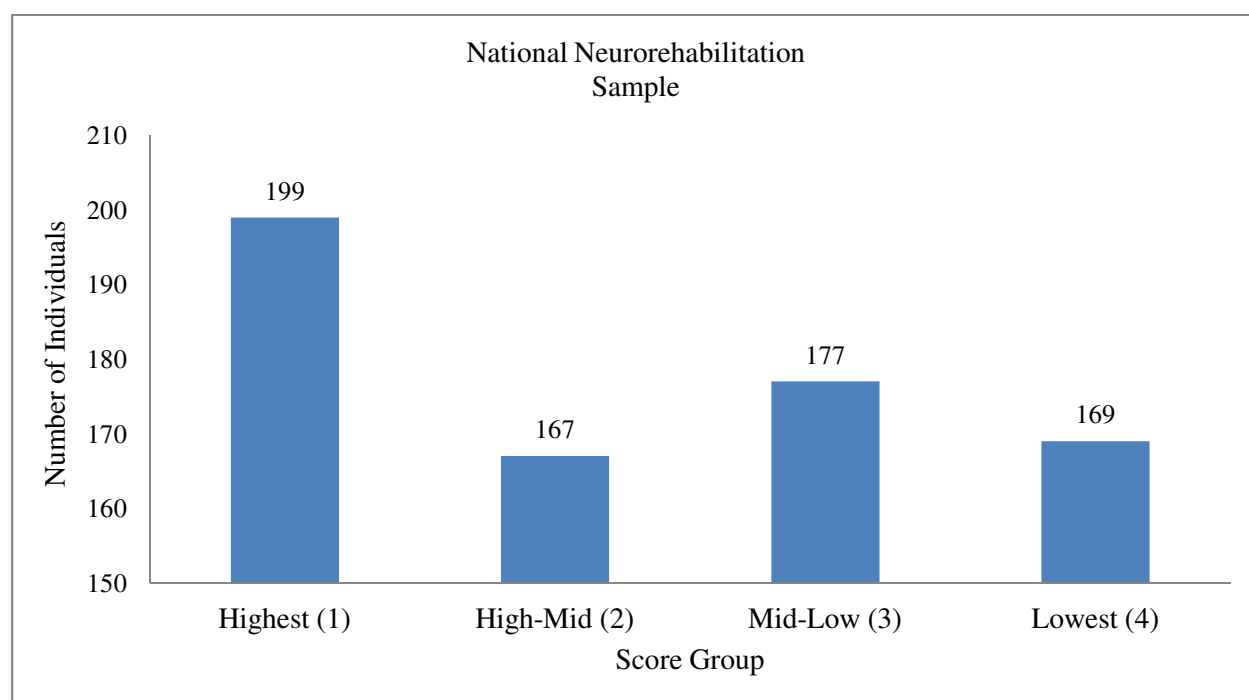
activity more than 75% of the time. Raw scores on the 29 items are converted to T-scores within three subscales: Ability Index, Adjustment Index, and Participation Index. Each index has an average impairment T-score of 50 and a standard deviation of 10 points. The T-score interpretation is inverted so that higher scores reflect greater disability. The MPAI-4 and its three subscales (Ability, Adjustment, and Participation Indices) offer well developed and documented psychometric properties as described in chapters II and III. Thus, participant functioning was assessed using the MPAI-4 at the time of admission and time of discharge from these treatment facilities involved in the study using a protocol developed and implemented as described below.

To identify the top performers, a change score was determined by adding the admission T scores of the items representing the scores in the categories of Ability, Adjustment, and Participation (the Total Score at Admission) and then subtracting from this score, the discharge T scores of the items representing the scores in the categories of Ability, Adjustment, and Participation (the Total Score at Discharge) for each of the 712 individuals who were treated at any one of the PHIDBIR-R programs during the period of time inclusive of the study's time period. The product of this calculation was used as the basis of rank ordering the subjects. These data are represented in Appendix F. A rank order of Mayo Portland Adaptability Inventory-4 (MPAI-4) change scores was performed for these 712 individuals.

The scores were arranged into four groups with the greatest change score group including 199 individuals. A decision was made to group participants into four groups based upon their falling into different change score ranges so that the highest (Group 1); the high-mid (Group 2); the mid-low (Group 3) and the lowest (Group 4) change scores could be identified for purposes of determining like or dissimilar demographic characteristics. The highest change score group (Group 1) represents those individuals who made the greatest gains as measured by the MPAI-4 during the time period of admission to discharge from the PHIDBIR-R program. Similarly, the lowest change score group (Group 4) represents those individuals who made the least amount of gains as measured by the MPAI-4 during the time period of admission to discharge from the PHIDBIR-R program. This division of scores into groups sets up the opportunity to compare groups. While not a part of this study, it is expected that I will, at a

later date, examine the experiences of individuals who fall into the lowest gains group (Group 4) and determine how these two groups (Group 1 and Group 4) differ in their experience of the PHIDBIR-R program.

The group representing the highest change scores were then again divided into four groups representing change scores reflective of the highest (Group 1a); high-mid (Group 1b); mid-low (Group 1c) and the lowest (Group 1d) change scores. The analysis is provided in three parts: 1) review of demographics based on National Group Analysis. This level of analysis statistically determines participants falling into 1 of 4 levels; 2) the upper group representing the individuals with the highest change scores (Group 1) was then dissected further to show the variability within the highest responders; and 3) a review of Participation values from the Mayo Portland Adaptability Inventory-4.



Group	<i>n</i>	Change score range	Mean change in participation T- score	SD
Highest (1)	199	12-34	16.5	4.6
High-Mid (2)	167	7-11	8.7	1.36
Mid-Low (3)	177	2-6	4.1	1.38
Lowest (4)	169	(-21.0)-(-1.0)	-1.17	2.9

Figure 4.1 National sample by number of individuals and groups. To identify the top performers, a rank order of MPAI-4 change scores was performed for 712 individuals who were treated at any one of the PHIDBIR-programs during the period of time inclusive of the study's time period. The scores were arranged into quartiles with the greatest change score quartile including 199 individuals.

The following analyses are provided to show the interaction of participant characteristics and outcome.

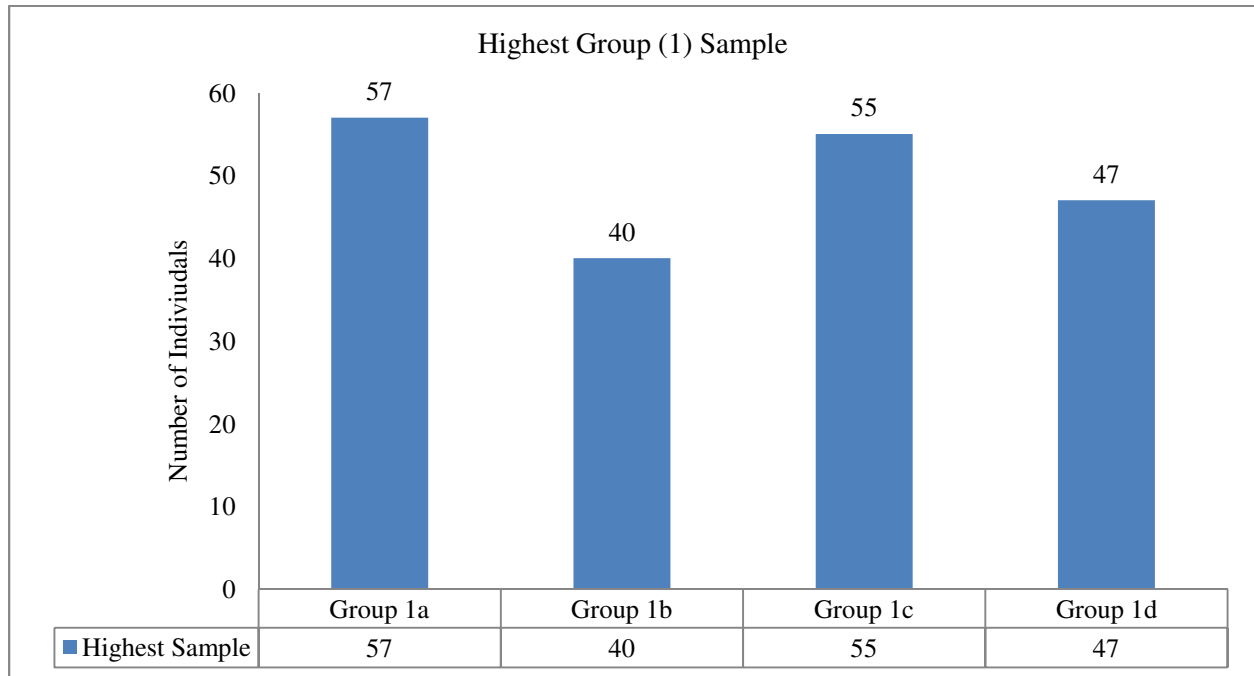
Table 4

Interaction of Participant Characteristics and Outcome by Group.

Characteristic	Highest (1)	High-Mid (2)	Mid-Low (3)	Lowest (4)
Sample Size	199	167	177	169
Age	43	45	43	41
Male / Female %	77 / 23	71 / 29	79 / 21	77 / 23
TBIs %	63	64	69	67
CVAs %	17	14	9	9
Anoxia / Hypoxia %	6	5	6	5
Length of Stay (months)	4.6	4.9	4.7	3.7
Onset of Injury to Admission (months)	10.2	22.9	30.7	27.0

Note. The majority of the individuals within this highest 25% (Group 1) were an average age of 43; male; presenting with TBI with an average length of stay of 4.6 months and average onset to admission of 10.2 months.

Within this highest change score group (Group 1), the greatest change scores were again analyzed to yield a rank ordered sample size of 57 individuals.



Group	Mean change			
Sample	N	Change score range	in participation T-score	SD
1a	57	19-34	22.31	3.99
1b	40	16-18	16.65	.735
1c	55	13-15	14.11	.831
1d	47	12-12	12	0

Figure 4.2 Greatest change scores of highest group sample. To identify the top performers, a rank order of MPAT-4 change scores was performed for the 177 individuals who were identified as being within the Top 25% of responders via MPAT-4 change scores during the period of time inclusive of the study's time period. The scores were arranged into four groups with the greatest change score group including 57 individuals.

The 57 identified individuals who represent (in rank order) the highest achievers were provided with gender neutral pseudonyms to protect the identity of the participants. Pseudonyms and Rank Order are noted in the data supplied in Appendix F.

Table 5

Interaction of Participant Characteristics and Outcome by Group 1.

Characteristic	Group 1a Highest 25%	Group 1b High-Mid 25%	Group 1c Mid-Low 25%	Group 1d Lowest 25%
Sample Size	57	40	55	47
Age	46	45	42	42
Male / Female %	67 / 33	73 / 27	86 / 14	83 / 17
TBIs %	68	63	66	53
CVAs %	14	23	11	21
Anoxia / Hypoxia %	2	5	11	6.4
Length of Stay (months)	5.1	4.7	3.8	4.8
Onset of Injury to Admission (months)	6.5	14.0	4.6	18.0

Note. Within this highest change score group (Group 1), the greatest change scores were again analyzed to yield a rank ordered sample size of 57 individuals. This chart shows the majority of the individuals within this highest group were an average age of 46; male; presenting with TBI with an average length of stay of 5.1 months and average onset to admission of 6.5 months.

Clinically, the best responders were shown to be those with either more focal traumatic brain injury or stroke, and admitted to any of the PHIDBIR-R programs within 6 months of the onset of injury. There may be an association of gender, though generally, the ratio remains 3:1 of male to female participants, and is reflective of the ratio of all individuals served within these national programs. The MPAI – 4 data for this group of Group 1a (Highest 25% of change scores), produced overall change scores ranging from 128 (highest change T-score within this group) to 44 (lowest change T-score within this group). It is noted that the sample size for each of the four groups does not fall precisely into equal

25% groupings. This is due to individuals' scores falling into four different ranges, making a precise 25% not possible.

While the total change scores in MP AI-4 are represented in the total T-score change, there is some information to be gained by further examining these data. The individual subscales categories of Ability, Adjustment, and Participation also informed the direction of qualitative data collection and provided additional color on the primary question "What are the components of the Post-Hospital Brain Injury Rehabilitation – Residential program that may contribute to these individuals' gains in function?" As discussed in previous chapters, the 29 items on the MP AI-4 are converted to T-scores within three subscales: Ability Index, Adjustment Index, and Participation Index. A question that may inform Phase 2 of the study emerged: "Which of the three subscales of the 57 highest performers (Group 1a) accounts for the most change?" To answer this question, a change score was determined by using the individual scores in the categories of Ability, Adjustment, and Participation and then subtracting from this score, the discharge T scores of the items in the each of the categories of Ability, Adjustment, and Participation for each of the 57 individuals identified in Group 1a as the highest performers. The results are indicated below.

Paired t-test for top performers (n=57). Three Paired t-tests were performed to examine the change from admission to discharge on Ability, Adjustment, and Participation T-scores. Improvement from admission to discharge on each of the MP AI-4 T-scores was statistically significant, Abilities $t(56) = 9.97$, $p < .001$, Adjustment $t(56) = 9.02$, $p < .001$, Participation $t(56) = 42.35$, $p < .001$. (See Table 6).

Table 6

Ability, Adjustment, and Participation T-scores

MPAI-4 Index	Mean Adm-D/C Difference	Standard Error Mean	<i>t</i>	df	Sig. 2-tailed
Ability	15.54	1.55	9.97	56	.001
Adjustment	11.60	1.33	9.02	56	.001
Participation	22.31	.52	42.35	56	.001

Table 7

Group 1a Total Change Scores in MPAI-4 Subscales of Ability, Adjustment, and Participation

MPAI-4 Index	Admission	Discharge	Change	SD
Ability	56.67	41.12	15.54	11.76
Adjustment	47.58	33.722	13.86	11.6
Participation	61.5	39.19	22.31	3.98

As the data demonstrate (Tables 6 & 7), the seven items that make up the Participation Index (inclusive of Initiation; Social contact with friends, work associates, and other people who are not family, significant others, or professionals; Leisure and recreational activities; Self-care; Independent living and homemaking; Transportation, Employment and Managing money and finances) are responsible for creating the most change in score. However, it is important to consider the interconnectivity of all items on the MPAI-4. That is, cognition items measured in the adjustment subscale may well drive community access scores in the participation subscale. The work of Lewis and Horn (2013) indicate that improvements in Abilities and Adjustment drive change in Participation, and this may account for the greatest amount of change being reflected in the Participation subscale. For the purposes of this study, themes included in items on the Participation subscale provided some direction to probing subjects'

responses in Phase 2 of the study to gain additional detail regarding their experiences of the PHIDBIR-R program.

Predictive findings. Step-wise multiple regression analyses were also conducted to determine predictors of Participation T-score at discharge (a measure of overall functional outcome). The first analysis was performed on participants in the Highest (Group 1) of the total sample (n=199). Person variables entered included: age at admission, chronicity (onset of injury to admission), and length of stay. Next, items from the three MPAI-4 indices were entered. Items from the Abilities Index were chosen in keeping with Lewis and Horn's (2013) findings of those items most closely associated with change and included mobility, motor speech, verbal communication, attention/concentration, memory and fund of information. Items from the Adjustment Index included: Impaired Awareness, Inappropriate Social, Anxiety, and Depression. Initiation, Self-care, and Residence (level of independence in the home) were included from the Participation Index.

This analysis, displayed in Table 8, identified six significant predictors of discharge participation T-score: self-care, initiation, residence, motor speech, mobility, and impaired awareness, $R^2 = .76$, $F(6,182)=91.7$, $p<.0001$ (adjusted $R^2 = .76$). Of those variables, self-care predicted the largest portion of variance in discharge participation T-score (adjusted $R^2 .517$). Initiation increased the prediction of discharge outcome by 18% and residence added another 4 percent.

Table 8

Six Significant Predictors of Discharge Participation T-scores

Predictor Variable	Stepwise Regression		Final Beta	P-Value
	R-Square Added	Cumulative R-Square		
Self-care	.520	.520	.298	p < .0001
Initiation	.177	.697	.369	p < .0001
Residence	.041	.738	.201	p < .0001
Motor Speech	.009	.746	.077	p < .01
Mobility	.006	.752	.114	p < .05
Impaired Awareness	.006	.758	.099	p < .05

The six significant predictor variables were then entered into a stepwise in a regression analysis to identify predictors of discharge Participation T-scores for the top 57 performers (Group 1a; Table 9). This analysis revealed three significant predictors: self-care, initiation, and residence, $R^2 = .87$, $F(3,53)=113.14$, $p<.0001$ (adjusted $R^2 = .86$). Self-care predicted the largest portion of variance in discharge participation T-score (adjusted $R^2 .72$). Initiation at admission increased the prediction by 10% and residence added 4% prediction of participation T-score at discharge for top performers ($n=57$).

Table 9

Predictors of Discharge Participation T-scores for Group 1a

Predictor Variable	Stepwise Regression		Final Beta	p-value
	R-Square Added	Cumulative R-Square		
Self-care	.73	.73	.457	p < .0001
Initiation	.10	.83	.377	p < .0001
Residence	.04	.87	.259	p < .0001

Phase 2: Experience of Rehabilitation Constructs

As explained in Chapter III, Phase 2 of the study was used to capture and describe the experience of the rehabilitation constructs. An attempt to contact all 57 individuals from Group 1a was made. Of this group, one had passed away; three indicated that they were not interested in participation; one was involved in a legal suit and felt participation in the study may negatively affect this; 31 had telephone numbers that were disconnected and 11 did not return multiple phone messages left. This produced a total of 10 respondents who agreed to participate in the study.

Each of the 10 individuals who participated in Phase 2 of the study was seen in their own home and informed consent was obtained. These 10 individuals resided in seven different states. An attempt was made to interview individuals separately from family members, however in three interviews, families wished to be present and offered their opinion on some of the questions. In each of these incidents, the information offered by family members probed a response or provided an additional articulation of the individual's response. Semi-structured interviews lasted 35 minutes to one hour and twenty minutes. The time required for each interview was based on individuals' communication speed, tendency for tangential speech and level of detail elicited. All interviews were tape-recorded and then transcribed.

Qualitative data were collected via semi-structured interviews with constant comparative analysis. As described in Chapter III, open and axial coding techniques were used to examine the interview data, beginning with initial codes that are analyzed into categories, themes, and idea clusters. Procedures to enhance trustworthiness, which is the qualitative counterpart to validity in quantitative design, include process notes, member checking, peer review and memo writing. A total of 18 process notes were written by the researcher and helped to standardize participant contact, review of informed consent, interview process and recording. Member checking was completed with two participants – Phoenix and Gray – and was found to have elicited 96% agreement across codes. This metric of 96% was determined via NVIVO-10 analysis of node coverage. The two notes of disagreement were details of participants' stories and did not affect category and theme development. One hundred percent agreement on category and theme descriptions was obtained via member checking.

Two peers, both psychologists with post-graduate education preparation, participated in peer review. Each reviewed two different coded transcripts. One reported 98% agreement with coding and the other reported 96% agreement as judged by NVIVO-10 analysis of node coverage.

Eleven memos were written and all described aspect of the interview with participants.

The following sections present the data analysis and are organized into four categories, each describing a major finding (Table 10). Emergent themes and idea clusters within the categories are given detailed discussion. Direct quotes are reported using the intelligent verbatim transcription style and are cited for easy transcription location. For example, (Harper, 17) indicates that Harper is the speaker and the quote appears in his/her transcript at comment #17 on the node in which the comment is ascribed.

Table 10

Categories, Themes, and Idea Clusters

Category (1, 2, 3, 4) Theme (a, b, c, d)	Idea Cluster 1	Idea Cluster 2	Idea Cluster 3
(1) Support			
(a) Paid Staff	Supportive Stance	Attitude	Skill
(b) Program Peers	Collectiveness Feeling	Competition	X
(c) Family Support	Frequency of Visits	Involvement in Treatment	X
(d) Higher Power	Saved from Death	Source of Strength	Control of Outcomes
(2) Therapies			
(a) Staff Skills	Specialties	Availability; Individual Treatment	X
(b) Self-Assessment	Describe Adaptation	Attitude of Self-Efficacy	X
(c) Equipment or Techniques	Level of Supervision	X	X
(3) Continuum of Care			
(a) Time of Treatment	After Hospital Experience	Community Integration	X
(b) Accessing	Real World	X	X
(c) Levels of Care	Progress in One Setting	X	X
(4) Environment of Care			
(a) Daily Schedule	Structured Day	Work Ordered Day	X
(b) Physical Set Up	Home-Like	Barrier-Free	X
(c) Location and Setting	Community Imbedded	Transportation	Proximity to Home

Category 1: Support

At the beginning of each interview, I asked participants to tell me about their rehabilitation experience at the PHIDBIR-R program. This open-ended prompt elicited general responses across all interviews that indicated the overall experience at the program was positive and effective. When asked about what helped to contribute to these positive experiences, all 10 participants made reference to the concept of support and help they felt as being a primary contributor to their successful improvement in functional challenges they experienced after brain injury. Four major themes related to the concept of support were revealed in the data. First, that staff at the PHIDBIR-R program provide support for success. Second, that peers in the PHIDBIR-R program provide motivation or support. The third theme indicated that family supports helped to achieve gains and the fourth, that a higher power provided success.

Theme 1a: Paid staff provided needed support. This first theme, which was noted by every participant and was also the most saturated throughout each of the interviews, established that staff at the PHIDBIR-R program provided support for success. Study participants described a total of three idea clusters of this paid staff support – supportive stance, attitude and skill. Every scenario recalled, regardless of the job function of the staff member involved, was characterized by study participants' perceptions of significant support that helped the participant to realize improvement.

Paid program staffs' support. Seven participants described how they felt that staff were positioned to help them in their recovery, and that they had a vested interest in their successes. Participants indicated that this was both motivational and gave them a sense of well-being and inclusion. In each case, significant actions on the part of individual staff were described as integral components of the rehabilitation experience. The narratives reveal that participants cared that staff cared about them and their experiences and success. Sawyer felt that staff support was imperative to recovery, noting "staff support is what helped me more than anything, because I'm like - they care. They talk with me and get me to do a lot of stuff and seem to care that I get it right. They were encouraging. They're not leaving me sitting in this room all day like in the hospital. I was out there participating even in neighborhood like

stuff” (Sawyer, 4). In this case, it was the staff positioning as having a vested interest and appearing to enjoy Sawyer’s successes that this participant viewed as contributing to his success. Reflective in Sawyer’s comments also, is the element of encouraging community activity and participation, which was determined to be the subscale with the largest change score (Participation subscale) in the MAPI-4 data findings as reported earlier in this chapter. Marion was initially more general with his comments about staff support, but became more specific: “Pretty much all of the employees there were very exceptional at their job. I just think they encouraged me just be to part of everyday life and that really helped a lot” (Marion, 1). Again, staff positioning as supportive and encouraging of participation in activity was viewed as a contributor to success.

Paid program staffs’ attitude. Five participants described in vivid detail, aspects of paid staffs’ attitudes which they felt were contributory to their successes. These attitudes were invariably described as “positive”, but had also elements of hopefulness, optimism and cheerfulness as described during interactions with program participants. Young recounts “I think they were purposely cautious with their presence when they were talking to somebody. If they were having a bad day they were still pissed, they must have got someone else to go work with me, because everyone was just really positive. I think they did that because we were all so busted the hell up... And if there's any kind of feelings, well we needed that positive demeanor” (Young, 2). Similarly, Phoenix noted that staff attitudes contribute to the environment of care that encouraged success: “It was really close-knit and everybody's wanting everybody to get better and really making us believe that we would. Good attitudes, I mean” (Phoenix, 4). The data also indicated that staff attitudes toward program participants showed a positive regard for them and created a living environment of dignity and respect. “Even some people, some of the other patients, granted they're injured, they're not as nice as day-to-day people but the staff always treated them like real people, so that always made me feel good about staff and that made me feel-- it felt good. It helped” (Young, 6). The theme of paid staffs’ positive attitudes marked by an expectation of gain/improvement was prevalent throughout these five participants’ interviews.

Paid program staffs' skill. While support and attitude were noted by the majority of participants as contributing to their gains, four participants spoke of individual staff members' skills as playing a role in their successes. Sawyer described a staff member who was integral in initiating a therapeutic relationship: "And she listened to me. I tell you what, that was the most important part of my time there, that she cared enough to listen to me because others at the hospital just kept saying, "No, you'll be okay." This example demonstrates what is described as staff support, but is also reflective of the skill that this paid staff presented in active listening and validating Sawyer's concerns (Sawyer, 8). Similarly, Kerry describes the skill that paid staff demonstrated in creating an environment of support: "All I can recommend for Neuro is to hire as many people just like them because they were very upfront but polite about telling me - hey, that was stupid, don't do that again. They never said it like that, but in a lot of cases I can look back and get that is what they meant. But it worked. It worked very well. I knew they had my back with that behavior stuff" (Kerry, 2). Angel noted that paid staff were conscientious, stating "the workers in Chicagoland were great - I know that. They definitely did their jobs well. I didn't notice anybody slacking. Ever" (Angel, 5).

Overall, these ten narratives depicted paid staff support in both general and specific situations. Study participants described staff support that showed a vested interest in participants' successes and was motivating and positive in the delivery of encouraging comments. Participants also described skill sets that demonstrated an ability to create and maintain therapeutic relationships, using active listening skills, good expressive communication and job duty conscientiousness. When participants described paid staff supportiveness, they provided details of encouragement they received to participate in real word community activity.

Theme 1b: Peers in the program provide motivation or support. The second theme, that peers in the PHIDBIR-R program provide motivation or support, was indicated by all but two study participants. The notion of peer interaction having an impact on the therapeutic environment is obvious. In a residential environment, this interaction may have the opportunity to produce an even greater effect, given that these individuals have the potential to interact with each other 24 hours a day/ seven days a

week. Participant narratives in the data set suggest that the motivation and support may also be gleaned by interacting components of peer relationships and by the environment created together with other program participants who are also recovering from brain injury. Two key idea clusters are evident in the data – the creation of a feeling of collective challenges being met and competition.

The creation of a feeling of collective challenges being met. Seven study participants described the positive effects that peers in the PHIDBIR-R program who were also recovering from brain injury had on their recovery. While they used phrases such as “inspirational;” and “very motivating”, it is clear from the data that the interaction they had with peers in the program helped to create an environment of camaraderie and expectation of collective success. One participant summed it up with a comment of “We’re all working on different stuff, but we’re all trying to get better here and get on with our lives.” (Phoenix, 4). Angel described his experience with one peer who he indicates was a catalyst for his own change toward a belief that he could improve. “When I met R, I got much more excited. He was hurt real, real bad. Much worse than me. But he was so positive, it was just incredible. I thought - If he could do it. He made the whole place better for us” (Angel 9). Similarly, Leslie indicated “there were people who I think were worse off than I was, but they were working hard so I thought that I would support that and I did too. (Leslie 4). This sentiment was echoed by Marion “I realized that there are some people even with harder times from the brain injury than I have, and they gave me confidence” (Marion, 2). Phoenix described the feeling of camaraderie as fellowship: “There was fellowship between the people there. There are some people there that I thought - Ugh, so many weirdos. But I’ve got to deal with them because they’re here, I’m here - it’s just one of those things. And then I ended up loving the experience now because we were in it together” (Phoenix 7).

Competition. The data also revealed that some competition between peers may have contributed to gains made. “On any given Tuesday, it was myself, B, D and G - which is a handful of personalities - and also F battling it out against whatever other team. And we usually ended up on the top. You can call

Coach C for validation, or any other of the OTs and PTs there. Those competitions were good” (Leslie, 3). This competition appears to not only been at times fun, but also motivating as Phoenix described:

Another guy - J. He was really interesting too because he was the first guy I met outside the building. I was there too and I met him outside the building. I started talking to him like I would any of my friends from high school, and he took to that right away. We were like instant friends.

But I also didn't want him to get better faster than me. So I worked hard. So did he. (Phoenix, 4)

Interaction with peers who are also recovering from brain injury appears to be a contributor to gains made in a program. Item 24 on the MPAI-4 requires a rating of social contact with friends, work associates, and other people who are not family, significant others or professionals. This question falls under the Participation subscale, which again, is responsible for contributing the largest amount of change in function, representing gains.

Theme 1c: Family support helped to achieve gains. Eight of the narratives made frequent reference to family support contributing to functional gain. Two idea clusters emerged from the data as contributing to these improvements: frequency of family visits and family involvement in treatment.

Frequency of family visits. Four participants noted during the interview that their regular face to face visits with family members contributed to their gains. Angel simply indicated: “They came to visit me a lot. It helped because I knew they were expecting to see me get better each time” (Angel, 5). Similarly,

Young revealed “My wife, she brought my kids to see me three days a week even though it was a two-hour drive to see me - two hours there, two hours back. That little play area that we'd go to with the kids, into the room, play in the-- with other stuff so it was good, helped relieve some stress and see the family and let me know I'm still important to them and that they still remember me even though I was having trouble remembering them” (Young, 8). For the four individuals who cited family face to face visits, it was clear that they believed that the frequency of contact was an important contributor to their success, rather than the activities in which they engaged during their visits.

Family involvement in treatment. Three participants made frequent reference to their family members' active participation in their rehabilitation program as contributing to overall gains:

My wife would bring groceries in, and we'd cook meals that we cooked before, just to stimulate my brain for what we've done in the past. We'd do asparagus or whatever. Salmon or shrimp or whatever. We baked it. The staff there encouraged it because I had to relearn it and it was with my wife and we weren't big spaghetti eaters. It was the food that we really usually eat. (Gray, 2)

Similarly, Marion indicated:

It was beneficial being close to family because I had that connection and they could learn all of my exercises and my strategies and help me with them when I went home on the weekends and even after I got discharged. (Marion, 4)

All three participants (Gray, Marion and Phoenix) identified family involvement in treatment as not only contributing to their gains, but being essential to their success, with all three noting that they "could not have done it without my family [participating in therapy]".

Theme 1d: A higher power provided success. Eight of the ten participants identified a higher power (in each case, God) as having ultimate responsibility for all of their successes. It is noted that the interview protocol did not ask a question about a higher power or God or about any religious beliefs. But in each case (Ryan, Emery, Angel, Gray, Phoenix, Sawyer, Leslie and Kerry), respondents indicated that God was essential in their success. Three idea clusters were revealed in the data: that God had made sure that the participant did not die in the injury and was guiding recovery; the participants' ability to call on God for a source of strength and the notion that they as an individual were not in total control of their lives or their outcomes. It is noted that not all of the eight participants who spoke about this theme held these beliefs before their injury.

A higher power guiding recovery.

He said something about being blessed and I was like, 'Oh, motherf*cker. He's going to be all into God and sh*t.' And that was when I was devoutly atheist and now I'm talking about God all

the time. It's because I can't really explain why I've done so good. At some point I started saying prayers, so it feels like they were answered. (Angel, 8)

God's plan for Angel was a central theme in his own recovery and success narrative:

I feel like God was training me my entire life to have a TBI. I was a rollerblader when I was six years old to when I was fifteen, then I was a skateboarder. When I was fifteen, when I was a freshman in high school, I started gymnastics. It was like God was setting everything up so that I could recover well from a TBI. I know that the being in good physical shape and having all those things that had to do so much with balance definitely made my recovery physically easier. (Angel, 1)

A higher power as a source of strength. Participants who made mention of their relationship with God contributing to their gains, described taking time for prayer every morning and throughout the day, and asking for help from God during these prayers. Phoenix indicated that his success was due to being able to call on a higher power during recovery “Yeah. You look towards Jesus Christ. My faith is very important. I see how important it was then, now. It has taken me until now to see how important my faith was in my getting better. I could always call on Him for help and I did that with prayer every morning and during the hard times in my day” (Phoenix 7).

A higher power in control. Six of the eight participants who felt a higher power was responsible for their successes also made reference to a belief that they as an individual were not in total control of their lives or their outcomes. Gray and Phoenix and Emery and Ryan and Sawyer felt that “God saved my life” and “I give all the credit of my success to God [or to Jesus Christ]”. “You never know what God's got in store for you, and you don't get to control it. He really helped because I asked him to” (Emery, 7). And “I put more of my faith in God and that took the isolation off my system, and then there was no real problem with me getting this stuff right, because I knew that He was in control” (Ryan 3).

Category 2: Therapies

When describing a PHIDBIR-R program, individuals often reference multiple therapies and disciplines that are provided within and embody the context of a rehabilitation program. Indeed, the very

notion of rehabilitation includes a guided opportunity for practicing and correctly demonstrating skill or ability output. Activities within a rehabilitation program are structured by staff in order to create an environment which focuses on the goal of improving functional skills or abilities and in which practice and feedback can be achieved safely.

All but one of the study participants specifically spoke about the therapies in which they participated while enrolled as an inpatient in the PHIDBIR-R program. Three themes of contributions to improvement in function emerged from this discussion on therapies: the developed skills of individual licensed clinician or trained extender staff, self-assessment, and effective use of equipment and program techniques.

Theme 2a: Individual clinician and extender staff skills. All but one of the respondents spoke specifically to the skills that the licensed clinicians or trained therapy extenders demonstrated at the PHIDBIR-R program. All who noted these skills as contributing factors to their successes identified individual staff members by name and gave examples of that individual's helpful behavior. Oftentimes, this was in the form of active listening or behaving in a manner that the study participant thought to be professional; the participant felt that he was treated with dignity and respect. For example, Gray (1) recalled: "coming in to talk with me, that was probably definitely helpful. For sure. Even speaking my mind with her about what I've been going through, and what's been helping and what hasn't been helping. Again that was some assistance." While Sawyer (2) mentioned:

The staff was professional. They always did what they were supposed to do, and always for me for sure, spoke professionally and appropriately with me. If I needed assistance with stuff, and I asked them about it, they would either help me or they'd give me assistance, or if they weren't sure, then they would talk your demands – or Mr. O. He's the one that said yes, it's okay. Don't give [Sawyer] assistance. We're going to let him do it himself.

From this reoccurring mention of staff skills and attributes, emerged two idea clusters: specialized therapies and the availability of individual treatment.

Specialized therapies. Angel, Marion, Emery, Leslie and Ryan discussed specific therapies as improving certain skill sets. These therapies, which included pet therapy, guided physical activity, vocational activities, anger management and talk therapy, at times involved specialized equipment and typically targeted one skill, such as hand strength or cognitive processing speed. Respondents, like Marion (2), also spoke of these experiences being enjoyable:

The therapist would do arithmetic, or talk, or whatever. Doing some fun drills, which were supposed to be exercise-related, pitching bags or playing a thought organization game type of thing, or something. Just things that were able to help you relearn or actually understand.

Interestingly, three individuals specifically noted pet therapy as contributing to their success: “we'd go out in the backyard and throw the ball and I would totally take care of him, brush him. We'd go for walks with him. I think that helped him out tremendously” (Sawyer, 4). Guided physical activity, as every participant noted, was also a strong contribution to their accomplishments: “the athletic exercise hour, I think it was usually 9 to 10 or 10 to 11. That was always very enjoyable and so helpful. It seemed to really help my thinking too” (Emery, 2). Another three individuals spoke to vocational activity, one stating: “for me, starting to work finally and finding a job that I enjoy and see a lot of places where I can grow and be better finally got me to be where I thought I was getting success” (Ryan, 2). Therapy aimed at anger management, indicated two participants, contributed to their success while one individual felt that talk therapy was essential: “I think, for me personally, it was really mostly the discussions I had with the psychologist and my behavioral therapist that helped me to get better” (Leslie, 2).

Availability and individual treatment. Four participants felt that individual treatment, as well as frequent and easy access to clinicians contributed to their successes. One mentioned:

They just have more one on one time than at the hospital. They had a lot more patients at [name of hospital] and the doctor recommended that I do these spring exercises twice a day, so I would do it on days when they could help. But at [name of program], I was able to do twice a day every single day. So that was very really good at getting success. (Angel, 3)

Another stated: “what was really awesome is that all the therapy people were all in the house. You really

just had to go downstairs, and they would actually work with me throughout the day, and it was like—they were all there and just worked on things throughout the day” (Sawyer, 3).

Theme 2b: Self-assessment. Six participants engaged in a theme I have labeled self-assessment. While none of the participants themselves specifically used the phrase “self-assessment,” this label is descriptive of the demonstrated behavior of looking into themselves in order to assess aspects of their improvements and challenges. During the interview process, individuals noted that thinking about their thinking helped them understand the goals of the rehabilitation program and fully engage with a plan of care. For instance, Sawyer (5) recalled:

I started to realize with the help of the therapy that, yes, my physical recovery is very nice, but it's not important compared to my cognitive recovery, to the things that I can do mentally with my brain. Speech therapy then became my most important thing, because I realized that I had to get that thinking better.

While Leslie (4) stated:

It helped when I started to understand that when things bother me I make an ass of myself very, very quickly. Nothing I do or say is good when I'm like that. When I let my emotions take control, I get myself in trouble now, so I am ready for that and I can back off.

Two re-occurring trends were noted in self-assessing individuals: an ability to describe an adaptation to a challenge or activity and the presentation of a self-efficacious attitude.

Ability to describe an adaptation to challenge/activity. Three study participants made frequent reference to and described, in detail, their own ability to evaluate themselves and then make conscious compensation for their challenges. This included modifying their activities or adapting to their environments in a new way. As Sawyer (5) explained:

After thinking about it for a bit, I took a pair of needle-nosed pliers put them in my left hand and then got the pliers onto the swivel. So, I was able to use the pliers as my left hand and then my

right hand is just as dexterous as it ever was. I was able to change that hook from a hook to a lure. That was big for me that I was taught how to figure stuff like that on my own. So my hand might not work perfect, but I can still get a job done, you know?

Marion (3), as well, mentioned: “it’s hard to spell things now with my cognitive changes, but I’ve got this phone and I speak it to my phone so it spelt it for me,” while Ryan (3) stated:

I thought ‘just figure it out on your lunch break or on your day out going there. Just walk around and start writing stuff down. I need a map. I do need to write myself a little map. It’s ok.’ Stuff like learning to do that helped.

“That’s one of those things I don’t let bother me anymore,” said Emery (2), “I just ask people to repeat themselves because it happens to me a little too often sometimes, especially when I’m with new words. It sounds like everybody is drunk to me. But learning to ask for repetition was really, really helpful the most.” Alongside the ability to describe an adaptation to a challenge or activity, comes varying attitudes.

Presents an attitude of self-efficacy. From the data emerged a cluster of participants who tied their success to their own efficacy. All but one of the individuals interviewed described a belief in his capacity to execute behaviors necessary to produce specific performance attainments and reflected a confidence in the ability to exert control over their own motivation, behavior, and social environment.

Angel (1) and Sawyer (3) articulated:

I accredit almost all my entire alcohol recovery to being positive because I was one of those guys who kept reflecting on past events that upset me, and those thoughts were never going to change the fact that this or the other thing happened and I got a brain injury because of it. When I finally let go and just said I’m not going to do this to myself anymore—my days are so much better.

(Angel, 1)

It was a comparison to where I was versus them. I realized really quick, ‘You’re going to pull out of it, [Sawyer], it’s going to be all right,’ but these people are here to make sure whatever they deem is necessary for you to pull out, they’re going to do it. So, whether you like it or not, just

deal with it, because they're professionals. They know a lot more about it because you're not the one that decided to bash your head in. They're getting me up and making me do stuff, and I'm going to do it because there's only one reason they're making me do it. It's for the good of me. I understood the structure that you have to follow, and don't fight it. And by buying in, I started to do the work, but it was me who did the work and I got myself better. (Sawyer, 3)

The data clearly demonstrated that study participants viewed their self-efficacy as a contributor to success.

Theme 2c: Equipment or techniques. Six participants referenced specific equipment or techniques as contributing to their success. The two most discussed therapy techniques were real world therapy in which individuals practice skill improvement in the environment that they will utilize the skill post discharge and the use of good communication between staff for maximum understanding and success. Phoenix (1) articulated:

They took an hour in the community to do things. All the staff were trying to be on the same page...which is very hard to do because you're dealing with so many different people and different personalities. If you work this shift—and you might not see Richard, but you might see Joseph or somebody else—you might not know new things that they've learned in Speech or whatever. That's the hardest thing. But overall, they did quite well in coming together and making it all work. It was just good that it was all real stuff that we were doing. Sure there were protocols, but we were practicing what we really needed to do when we got home.

In addition, several individuals (Gray, Emery, Ryan and Sawyer) rapidly named equipment, activities and techniques that they felt helped: “cooking together was helpful;” “...you're always practicing what you're doing;” “went golfing;” “practiced driving with go-karting at Thunder Valley;” “ladder golf and cornhole bean bag was actually really good because it helped;” “all of the [physical therapy] stuff;” “mind games;” “memory activities;” “all of the cognitive exercises;” “[using a] dry erase board;” “anything visual;” “the

work crew program;” “all of the physical stuff that helps relieve stress and things like that;” “the number one thing is some sort of psychology, mental health.”

Level of supervision. With the use of specialized equipment or techniques, comes mention of the appropriate level of supervision. Three individuals described that a progressive decrease in their level of support and supervision was helpful and that as they progressed at their own rate; a greater level of independence was expected.

It was weird being there at first and people basically wanted to shackle me, it seemed. Not literally, but it was just like, why can't I walk around town? Why does somebody have to follow me? I don't understand that. There was no practicality behind it whatsoever I thought at the time. But then they helped me see that I was not looking before I crossed the road and I would get lost and I didn't know why I was going someplace or other. So, when I got better, I started to do some things without someone always with me. But that was only after I showed that I could handle that. (Kerry, 1)

Kerry was not alone—individuals consistently reported their initial frustration with this close support and supervision, but also reflected that they were able to later see a good rationale for this progressive decrease, based on personal safety and opportunity for guidance in practice.

Category 3: Continuum of Care

Five of the individuals who participated in the study provided comments about the program and its placement within the continuum of care -- experiences that are typical following brain injury. The continuum of care is a concept involving a system that guides and tracks patients over time through a comprehensive array of health services, spanning all levels and intensity of care. Individuals who participated in therapies at the PHIDBIR-R programs included in this study received, at minimum, immediate healthcare at an acute care hospital following their brain injury. Most participants were discharged from that environment to a rehabilitation hospital for a period of time before admission to the PHIDBIR-R; some were inpatient with several healthcare providers prior to their admission; and some

participants may have been admitted to a skilled nursing facility, participated in another PHIDBIR-R or discharged to their home before admitting to the PHIDBIR-R involved in this study.

Theme 3a: Timing of accessing treatment is important. Three study participants discussed that the timing of their admission into the PHIDBIR-R program was important in their successful recovery. Three idea clusters emerged from the data: that they were able to access the PHIDBIR-R program as a transition from a hospital based program; that they were at a point in their recovery that they could benefit from activity in and access to the community; and that the opportunity to be re-admitted into the PHIDBIR-R program now, at this point in recovery, would produce even greater gains.

After a hospital experience. Two study participants referenced that the timing of their transition from the acute or rehabilitation hospital to the PHIDBIR-R program contributed to their successes. “I had a perfect transition from hospital living to [name of program]” (Emery, 2). By “perfect,” Emery indicated that the timing and preparation for a change from a large medically based environment was helpful.

Angela (2) stated:

I knew it was time for me to make a change because I was going from being having nurses do everything for me, to go to more the intermediate kind of thing where I could do some things. It was time.

One of the participants likened the placement of the PHIDBIR-R program within a continuum of care to “like a halfway house for addiction, but for TBIs” (Angel, 3).

At point in recovery where they could access community. Two individuals recognized that they were at a skill and tolerance level in their rehabilitation where they could benefit from activities in and access to the community, and that this timing contributed to their improvement:

I could have never done grocery shopping or re-learned how my checking account worked at a real bank when I was first coming out of my accident. I had to wait to get more better before I could come here and do that. I wasn’t ready then. (Leslie, 2)

Opportunity to return. One individual discussed that while participation in the program did result in functional successes, that the opportunity to return would provide for even greater improvement.

“I think if I went back, I could probably use the wealth of success I gained from the first time, and jumping into a bigger wealth of success. I can still get better than I am today” (Phoenix, 1).

Theme 3b: Accessing this level of care as part of the continuum helps.

All five of the participants who noted details about the continuum of care as helping, spoke specifically about experiences in the PHIDBIR-R level of care as contributing to success. Angel (1), Phoenix (1), Emory (1), Leslie (2) and Ryan (1) alluded to their experience in this level of care as being entirely different from that in a hospital, a rehabilitation hospital, or a day treatment program:

It’s more intense because it’s all the time, which is different from the hospitals because you are still getting better from being really, really sick. This is a different type of getting better. Not just healing your bones and your skin and stuff, but now you’re thinking you know? (Ryan, 3)

One idea cluster emerged – That the PHIDBIR-R program is a real world experience as opposed to other environments of care within the continuum that operate in a contrived environment.

Real world experiences. Two participants explained that their rehabilitation experiences were based in a community environment, which provided a progression from contrived environments in a rehabilitation hospital, where the community is mimicked for safe practice, but does not actually take place in the “real world.” As Ryan (3) explained:

I was learning to cross the street there in this place in their gym that was set up to look like a street. But there wasn’t real traffic and I didn’t get confused by all the sounds and the people like I did when I started going back out into the real world. It was good for me to get back into that with getting help. Otherwise, I might not want to get back out there again.

Theme 3c: Providing different levels of care within the program helps. Three participants described that the levels of care within the program changed as their individual skills, safety awareness and independence changed. Two of the three described how physically moving locations when they had met some of the criteria of improvement was not only motivating, but contributed to success.

...but that was really cool how I started out on the first floor in room eight. Then after a while they moved me over to M's room, which was-- they moved M somewhere else and moved me to

M's old room. M's old room was huge. It had a big sized fridge in it and a small kinda kitchen. I was getting better then and could do some more cooking stuff with the microwave and stuff then and I needed to be able to practice in the type of place that I was going to live in when I left there. Like the type of place that I live in now. (Phoenix, 2)

Another participant commented:

But it was the perfect setup, overall, for me to continue to make me have gains. Having the third floor, where it was like progress and you could see it and you were actually going up because you were all together downstairs, well you had your own room, but it wasn't an apartment.

Downstairs, there was someone with you 24/7, but upstairs, you had some time that you were not always watched. (Ryan, 6)

Allows progress to happen in one place. One participant indicated frequently, that having access to therapy and community and healthcare and meals and room and board was convenient and fostered an environment of focus, while minimizing transportation fatigue as experienced in an outpatient model of therapy delivery:

Okay, I'm kind of a different case than a lot of other people that have had brain injuries, because I spent time in the ICU, then I transferred [name of hospital] and I spent about four weeks there before I transferred to a day program and then that was way too much with having to be in all of these different places for all these different appointments. It helped with I got to go to [name of PHIDBIR-R program] because it was all there and I could just worry about doing the practice and getting better and I wasn't missing any appointments of anything like I was. (Marion, 1)

The concept of continuum of care, inclusive of timing, access to the level of care within the continuum and different levels of care within the program itself are constructs that participants identified as contributing to their success in brain injury rehabilitation.

Category 4: Environment of Care

All participants made reference to aspects of the environment of care, inclusive of daily programming and the set up of the physical plant as contributing to their functional gains. Themes that emerged from the data included program schedule use, program set up and the location of the program.

Theme 4a: Following a daily schedule helps. Six individuals made frequent reference to following a schedule that kept them busy throughout the day. Two idea clusters emerged from the data: the concept of a structured day and the idea of a work ordered day.

Structured day. Two participants spoke about the day as a planned and predictable routine.

Leslie (2) mentioned:

It helped me to know what was going to happen from minute to minute. I could plan on it because new was hard for me then. Also, I got so that I was in a regular routine like I was in my life before (Leslie, 2).

One participant, Sawyer (2), likened both the structure and intensity of the rehabilitation program to a military exercise: “The day looked like a civilian boot camp.” Indeed, just having a predictable schedule that imposed order and structure on participants’ time was noted by one individual to be very helpful in achieving results: “What made it happen was just the schedule. The schedule, schedule, schedule good, which every person needs. And knowing your schedule, having it up on the whiteboard. That helped” (Kerry, 2).

Work ordered day. Six individuals described the ordering of their schedule, with one making reference to this order mimicking a job where there is structure and a process. For this reason, I have called this idea cluster work ordered day.

Your schedule, it’s like a real job. You get up at seven or something, shower and get ready, eat breakfast, then you make your way over to the treatment center because that’s where the therapists are and you hang out there and you usually see your physical, your occupational and your speech therapist, all in one day, and you get lunch over there. Then you do some groups and go into the community to get things done and have appointments and get back to the house

around 4 PM and you can rest and eat dinner and then people come and visit in the evening.

(Angel, 1)

Theme 4b: The physical plant or set up of the program helped achieve goals. Seven study participants cited aspects or details of the building structure or the way in which the rooms and equipment were organized and set up as contributing to their gains. One comment made by all seven was that having access to their own space, a single occupancy bedroom, was an important feature for their day-to-day comfort: “I had my individual room. It was nice, because I was there inpatient, and I had my own room and my own little space I could be by myself - go and get away if needed to” (Young, 2).

Home like. Six respondents commented that the environment of care was designed to be homelike and that this helped in their transition back to their private homes. That is, the physical set up of the environment was laid out to encourage shared common areas, a non-industrial style kitchen, private bedrooms and a flow that felt like a private residence:

It was a regular-- It was a house like this one I live in now, except with a ramp in front and you got much more one on one time. It was more like being at home. That helped because it was real.

(Angel, 4)

Another participant, Phoenix (5), made reference to the non-clinical environment that contributed to a homey feel of the environment of care:

The one thing that sticks in is, it was like a home - not the sterile, cleanly, clean room situation in a hospital. I had a full efficiency, nice kitchen, decent appliances - all kinds of good stuff. It was like a family and it was not so peculiar because you feel like you're home. Because the point of it was to go and get rehab and make gains and then go back home to the same kind of set up.

(Phoenix, 5).

Barrier free. One individual, Marion (1), noted many times throughout the interview that living in a barrier free environment of care, one in which wheelchair users could complete daily living activities such as bathing and meal preparation by easily negotiating spaces, was a contributor to success: “It helped

that I could just wheel into the shower, but it was in a home. I knew that I could get that when I was home then too” (Marion, 1).

Theme 4c: Location/setting of the program contributed to success. Nine study participants referenced the location and setting of the program as influencing their rehabilitation outcomes in a positive way. Three idea clusters emerged from the data: the program being imbedded in the community; transportation availability; and proximity of the program to their homes.

Imbedded in the community. Five individuals referenced their ability to live in and have immediate access to the community during their PHIDBIR-R experience as contributing to success. As Ryan (1) asserted: “Being in a neighborhood felt very good.” Participants indicated that engaging in typical routines in the community allowed them to getting back to a sense of normalcy, and that this helped improve their skills:

Yeah, going over to the YMCA every day at one I really liked - it might seem strange but - I really liked my trips to CVS right down the street, maybe a block away to CVS to go get my toiletries and stuff. You know shampoo, body wash. Having everything right there outside the front door is just a premier situation. If I would've been in a hospital and then I probably never would have met anybody to practice this stuff. (Gray, 1)

The idea of community participation was echoed by all, but was respondent of and is reflected in the high improvement scores of the subtest Participation in the MPAI4 as referenced above. Individuals spoke of both a general sense of belonging or being part of a community and also about specific activities they were able to enjoy due to the programs’ location of being in a neighborhood with easy access to amenities:

Yes, that's very important to get out and walk. I did a lot of walking for my own personal patience and own personal recovery. So get out and walk I did that every day. And then to have the staff come out and walk us down to the store, [I] think a hospital would have been more restricted and not as much getting out and doing more stuff outside of the hospital, in the community where I felt normal again and like I started to fit in. (Phoenix, 3)

Transportation availability. Three study participants gave brief mention to the availability of public transportation, such as buses or the metro, and public transport accessibility programs as aiding in their recovery:

I wasn't able to take buses by myself. It was a couple of months later that I got to that point where I could and was big to learn because I use them now. At first I wasn't even allowed to leave my neighborhood. I wasn't allowed to cross the big roads; the big roads were too dangerous. But soon after that, I'm just thinking of, getting along on your own with transportation was important. (Angel, 2)

Proximity to home. Two individuals advised that the program's close-to-home location was important. One indicated that it was a contributor to success: "Being right there – It took my family 20 minutes to get there – so they could participate in everything and I saw them every day" (Emery, 1). Young (1) indicated that if the program were closer to home, it would have both benefitted family members and minimized distractions around family transportation: "It was hard to drive two hours there and two hours back with two screaming children because they were four and two at the time. Really hard on my family and I knew that. Closer would have been better" (Young, 1).

Chapter Summary

This chapter presented the results of the data analysis. Change scores data representing improvement in function from admission to discharge were collected via MPAI-4, identifying 57 program participants who had made the greatest functional and statically significant improvement in Ability, Adjustment, and Participation from the time of admission into the program to discharge. Three Paired t-tests were performed for these top 57 participants to examine the change from admission to discharge on Ability, Adjustment, and Participation T-scores. Improvement from admission to discharge on each of the MPAI-4 T-scores was statistically significant, Ability $t(56) = 9.97$, $p < .001$, Adjustment $t(56) = 9.02$, $p < .001$, Participation $t(56) = 42.35$, $p < .001$. Regression analysis revealed three significant predictors: self-care, initiation, and residence, $R^2 = .87$, $F(3,53) = 113.14$, $p < .0001$ (adjusted $R^2 = .86$). Self-care

predicted the largest portion of variance in discharge participation T-score (adjusted R^2 .72). Initiation at admission increased the prediction by 10% and residence added 4%.

The primary purpose of this study was to understand contributing factors and experiences associated with a decrease in disability for those participants of a PHIDBIR-R program. Qualitative interviews with ten individuals were conducted from this group of 54 participants. Additionally, the investigation explored the methodology process itself as specific to the brain injury arena - how qualitative interviews with brain injury survivors and their families treated in a PHIDBIR-R program contributes to a more comprehensive and nuanced insight regarding the survivors' functional improvement. Participants were interviewed via a series of open-ended questions about their experience in the PHIDBIR-R program and asked to identify those elements of the program which they felt contributed to their successes and gains made. I used open and axial coding to examine recurring patterns in the data.

Thirteen themes within four major categories were reflected in the data. These themes represent participants' supports: family members, paid staff, peers within the program and a higher power; therapists' skill sets, engagement in self-assessment, as well as equipment or techniques; accessing a continuum of care, different levels within the continuum and timing of access and the environment of care's physical location, set up and scheduling of all activities. Participants described a wide range of experiences that included a host of positive contributions to their increase in function following brain injury. Discussion of the results, including methodological considerations and future implications, appears in the final chapter.

CHAPTER V

Summary, Discussion, and Recommendations

The results of the data analysis appeared in the previous chapter. In Chapter V, the findings are discussed. The chapter begins with an exploration of methodological considerations and study limitations. Next, I present a brief summary of the thirteen emergent themes, followed by an explanation of implications of the results for Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation – Residential (PHIDBIR-R) providers. Finally, the chapter concludes with specific recommendations for future research.

Methodological Considerations and Limitations

The primary purpose of this explanatory mixed methods study was to identify those specific constructs of PHIDBIR-R programs that contribute to an individual's gain in function. As the researcher, my ultimate goal was to promote action in applying the identified constructs as pillars of inclusion in the PHIDBIR-R program development across the United States. I was also interested in better understanding the methodological process itself as specific to the brain injury arena - how qualitative interviews with brain injury survivors treated in a PHIDBIR-R program contribute to a more comprehensive and nuanced insight regarding the survivors' functional improvement.

Research design. The research employed an explanatory mixed methods design with two phases. Phase 1 of the study was a quantitative design, which was used to identify and select the individuals who would participate in Phase 2 of the study, a qualitative design. This first quantitative phase used a repeated measures design to compare scores of the MPAI-4 at admission and at discharge, which identified those individuals who made the greatest gains in function while participating in a PHIDBIR-R program. By subtracting the T-scores at discharge from those taken at the time of admission, I rank ordered all eligible participants who were served during the inclusive time period. By then assigning each individual to one of four categories of highest to lowest achievement, I looked at the demographic differences of these groups and determined if there were differences. Additional analyses

were completed to 1) further understand which parts of the MPAI-4 showed change and, using paired t-tests, determine if this change was statistically significant and 2) determine which of the 29 items on the MAPI-4 contributed most to change scores using multivariate analysis of variance (MANOVA).

The 57 individuals identified in Phase 1 of the study were rank ordered from greatest change in score to least change in score as measured by the MPAI-4. These individuals were then contacted, beginning with the individuals with the greatest change scores, to determine if they would agree to participate in Phase 2 of the study, a qualitative data collection involving semi-structured interviews with the identified top performers. Ten individuals were interviewed. Saturation of themes began to be observed in interview four and was confirmed after interview six. Ten interviews generated a sizable amount of data and these were used to identify emerging themes of the rehabilitation program associated with functional improvement via identification of common and individual themes, representing constructs of the PHIDBIR-R program.

Reflecting on the mixed methods design choice, there are at least six distinct advantages. First, the two-phase approach enabled me to establish and maintain a reliable system of data collection and reporting of outcomes (Phase 1). Second, these data could be analyzed to determine overall efficacy of treatment and allowed me to look carefully at contributing areas of function improvement. Thirdly, outcome scores pointed toward the population who was of interest: individuals who made the most gains in function following treatment. Fourthly, Phase 2 of the study allowed me to explore the phenomenon of interest from the program participants' vantage point. Fifthly, the methods used generated sufficient data to answer the primary research question. And finally, the research design made it possible for me to make sense of the data.

Phase 1 of the study required the systematic collection of data and was achieved through the quality assurance and improvement plans of the company where all data were gathered and reported. This quantitative phase required extensive training of all staff involved in data collection and the establishment of a reliability system and data housing system. These data could then be extracted and inquiry could be made via SPSS query. Phase 2 of the study required a significant amount of time and

effort given that amount of travel to see the individuals interviewed and coding required for all data collected. In analyzing the data using the constant comparison method, I compared one segment of data to another to identify similarities and differences between them and then grouped similar ideas together to form clusters of these ideas. I identified recurring patterns or themes that linked clusters together. Finally, I recognized four major categories in the data. All data analysis procedures for both Phase 1 and Phase 2 of the study were efficacious in providing a framework for organizing and managing a substantial amount of data, and in answering the question guiding the inquiry.

Limitations to the research design. At the same time, this approach had limitations. First, participants of this study are limited to the experiences they have had at one PHIDBIR-R program operated by one company that provides multi-site PHIDBIR-R environments of care, which may reduce the generalizability and transferability of the findings. Also, the study focuses on absolute magnitude of changes in outcomes scores and does not take into consideration the rate of change. Testing occurs at admission and discharge only, so the study cannot identify when during the rehabilitation process the biggest changes occur. Data specific to participant history prior to admission to the PHIDBIR-R program inclusive of highly detailed injury characteristics, amount and type of rehab services received before admission may not be available for all participants and therefore cannot be included in analysis. The research does not account for spontaneous recovery following brain injury. In addition, while the data in Phase 2 are organized into groups and categories, these data units are not mutually exclusive or linear. Rather, the participants' detailed comments suggest that the categories and themes are all interrelated in important ways. According to Merriam (2009), a researcher could develop a model using grounded theory to understand the relationships between categories and subcategories. This level of analysis was beyond the scope of the current investigation. Therefore, one important consideration is that the study was not designed to explore interrelationships in the data or develop a theory about how the interaction of constructs of a PHIDBIR-R program work to achieve improvement. The study was limited to identifying those details of a program that participants felt aided the most in their successful recovery.

Participant selection. Phase 1 of the study included 712 individuals who were served during the study's time period. Eligibility requirements were: (1) the individual was treated at any one of the NeuroRehabilitation PHIDBIR-R environments of care operated by the company and (2) the individual was aged 18 to 70 at the time of treatment. The intent of the study was to understand successful program completers' experiences of the PHIDBIR-R program and identify those constructs that were most helpful in propelling their success. Phase 2 of the study identified 57 individuals as participants. Participation in Phase 2 included an additional eligibility requirement: the desire and ability to participate in one qualitative interview and, potentially, a member-check-in. The sample was primarily Caucasian (9) and male (8).

Limitations to participant selection. The findings may not accurately reflect the experiences of participants who do not identify as male or Caucasian. Furthermore, during data analysis participants were assigned gender-neutral pseudonyms, which were used during the peer review process. While this strategy may have been helpful in reducing the potential for gender bias during the peer review process, gender-neutral treatment of the data ignored the influence of gender—not only on the experience of PHIDBIR-R, but also on the research process itself.

Additional limitations were self-selection and self-report. Participants who were successfully interviewed in Phase 2 of the study agreed to participate, understanding that the primary purpose was to explore their experiences during the rehabilitation program. Some individuals contacted declined to participate on the basis of many different factors and therefore, the sample only included participants who had these experiences and wished to talk about them. During the interviews, participants were asked to recall their experiences in the PHIDBIR-R program. Since the phenomenon of interest occurred in the past, participants may not have accurately recalled earlier thoughts or feelings. In addition, self-report may lead to biased responses as participants may have responded to interview questions based on social desirability factors, a desire to help me with the research, or both.

A primary challenge of completing this study concerns my role as researcher. I am a licensed clinician and hold an executive leadership role in the company where all participants received their

rehabilitation supports and services. As an insider, I brought to this study certain biases, assumptions, and experiences related to 23 years of experience in working in brain injury rehabilitation. Truly - when I began this inquiry, I did not anticipate the impact it would have on me personally.

While immersed in my company's mission and at all times cognizant of the unique challenges each individual with brain injury faces following his brain injury, this researcher was not prepared to see on an intimate level, and in such rapid succession, reflections on those programs that she helped to create, maintain, and recruit participants. The researcher felt superlatively invested in her role as a provider of brain injury supports and services, but also as an advocate for recognition of brain injury as having parity with all other medical diagnosis and disease processes. As a researcher, she was committed to maintaining a stance that was most conducive to gathering highly descriptive data. However, at times she wanted to join the conversations, share accounts of others she has witnessed having similar challenge, or continually compliment the participant on their astuteness of observation or perseverance in times of significant challenge. To address these personal reactions, the researcher continually engaged in a process of self-reflection. Writing in a research journal and creating memos was helpful in processing much of this information (Lincoln & Guba, 2000). She also relied on peer reviewers for their perceptive feedback and willingness to walk with her through the transcripts she requested them to review.

Despite the limitations, this study has generated a great deal of relevant information. The findings are significant and have important implications for PHIDBIR-R providers, individuals served, their families, funders and all stakeholders. The major discoveries are summarized in the following section.

Summary of the Data

The data showed that individuals who made the greatest improvements as measured by the MPAI-4 experienced fewer problems in the areas of self-care, initiation, and residence when compared to the other 26 items the test measured. That is, these three categories account for the most amount of change in MAPI-4 scores among those who were determined to make the greatest improvements. Study participants then self-identified 13 major themes within four major categories, which are reflected in the qualitative data. Themes represent participants' understanding of details of their PHIDBIR-R program

that they associate with their successful outcomes. The 13 that emerged from the data as contributing to gain are: paid staff provided support; peers in the program provided support; families of the participants provided support; a higher power provided support; the skills of the paid staff helped; the ability to assess oneself was of benefit; particular equipment or techniques contributed to success; the timing of accessing the PHIDBIR-R program was important; accessing this level of care as part of a continuum was a factor; providing different levels of care within the program was a contributor; following a daily schedule helped; the physical plant or set up of the program was a contributing factor to success; and location of the program lent itself to goal achievement. These findings are highly robust throughout the data. The results support a framework for new program development—pointing towards compulsory construct inclusion, training, supports, and services in PHIDBIR-R programs.

Discussion of the data. In Phase 1 of the study, the 712 individuals were separated into four descending categories based upon highest to lowest outcomes scores. There were no observable demographic differences between these four groups, with the exception of average time of onset to admission (in months). The individuals within this highest achieving group (Group 1) were an average age of 43, male, and presenting with TBI with an average length of stay of 4.6 months and average onset to admission of 10.2 months; the lowest achieving group showed an average age of 41, majority being males, and presenting with TBI with an average length of stay of 3.7 months and average onset to admission of 27 months. The length of onset to admission is in keeping with both Lewis and Horn's (2013) and Braunling-McMorrow, Dollinger, Gould, Neumann, and Heiligenthal (2010) findings, noting that those individuals who access specialized brain injury rehabilitation environments of care earlier in their recovery make greater gains. As noted by Lewis and Horn (2013) in the *Journal of Special Operations Medicine*, those receiving services within eight months of onset of injury to admission demonstrated the combined effect of therapeutic gain with time. Those accessing the PHIDBIR-R level of care beyond eight months since injury continued to show progress but without time being a significant factor in recovery. Their data also substantiated further that once a person showed a year of recovery then continuation of that recovery was based on therapeutic intervention and application of skills, with time

having no effect on recovery of functions. The demographic data of the current study support those findings.

Within this highest change score group (Group 1), the greatest change scores were again analyzed into four categories of highest to lowest performers to yield a rank ordered sample size of 57 individuals. This group of 57 individuals' demographic information varies slightly with the lowest performing category of these overall high performers. The highest performers had an average age of 46 compared to 42 of the lowest performers. Both groups consisted of about the same majority of men and TBI injury (versus stroke). Average lengths of stay were similar with 5.1 months for the highest performers and 4.8 for the lowest performers in this high performing group. Again, the greatest discrepancy was in time of injury to access of PHIDBIR-R care, with the highest group of performers averaging 6.5 months of delay and the lowest performers (still of the highest performing group) averaging 18 months. As noted above, this is in keeping with previous research findings: those who access a PHIDBIR-R sooner make greater overall gains. The length of stay, that is the amount of treatment provided, does not appear to influence scores as greatly as the amount of delay an individual experiences from injury to PHIDBIR-R access.

The group of 57 highest performers was further analyzed. Paired t-tests data showed improvement from admission to discharge on each of the MPAI-4 T-scores was statistically significant in all three subtest categories of Ability, Adjustment, and Participation, with participation showing the most change (improvement) in score. Regression analysis revealed three significant predictors: self-care, initiation, and residence, all of which are included in the participation subtest. Self-care predicted the largest portion of variance at 73% in discharge participation T-scores. Self-care involves rating skill in completion of activities such as eating, dressing, bathing, and hygiene. This finding is not surprising as independence and safety in these types of activities of daily living is a primary focus of rehabilitation programs. Initiation scores at admission increased the prediction by 10% and included rating an individual's ability to get started on activities without prompting. This finding indicates that an individual's predictor of success may be tied to an ability to self-initiate activity (Lewis & Horn, 2013). Finally, residence—responsibilities of independent living and homemaking such as meal preparation; home

repairs and maintenance; and personal health maintenance beyond basic hygiene including medication management, added four percent. These types of instrumental activities of daily living are essential for independent living and health maintenance. It was useful to learn of these three predictors as they would helped to guide and shape some of Phase 2 of the study, which required an intensive individual interview of program participants' experiences in a PHIDBIR-R program.

Discussion of the Findings

Support. The first major category of findings, representing both saturation throughout interviews and consistent notation across all subjects, reflects the participants' understanding and experience of support. Results suggest that the concept of support, including providing encouragement, assistance and reinforcement while demonstrating an attitude of caring and personal investment in successes, is a contributor to individuals' success. Four themes about support emerged: firstly, that paid staff are supportive; secondly, that peers in the PHIDBIR-R program provide support; thirdly, that family members give support; and lastly, that a higher power plays a supportive role.

Paid staff. The data show that participants consistently describe positive interactions with paid staff, which results in their feeling that these workers have a personal investment in their success. This is the single most consistent theme found in the data and runs across all sources and details highly descriptive narrative. Participants describe staff assistance as being highly motivating for their full participation in activity and credit this support with creating positive forward momentum in the day-to-day activities of their programs. The supportive stance that staff adopt, a positive attitude, and individual and collective staff skill is credited with much of the success that individuals experience. Specific examples of how staff create and maintain this environment of staff support include: facilitating daily activity that engages and motivates, such as increasing physical activity; promoting nutrition and focusing on improved self-care safety and independence; celebrating successes and setting small attainable goals; and consistently demonstrating patience.

Implications. The staff's primary responsibilities at the PHIDBR-R program are to ensure safety, treat every individual with dignity and respect and to create an environment of care that encourages individuals to take an active role in their own rehabilitation. While data indicate that this program construct is the most referenced theme that participants tie to their successes, the provision of staff support may not be specifically taught at all programs and may be created differently in different environments or care. A review of staff training modules that address aspects of staff support show that training focuses on: an empathetic understanding of brain injury and how losses affect individuals and their families; supportive communication styles; and proactive behavior change support.

Results from this study reinforce the importance of intensive training for all paid staff at PHIDBR-R programs on their direct interaction styles and motivational supportive stance. All must understand that their pragmatics have the power to enhance individual outcomes and that this opportunity can be missed. Paid staff training focus can include activities that are used to promote improvement in interaction styles, participant engagement strategies, supportive positioning, and positive practice. Activities aimed at developing an empathetic understanding of participants' support needs may be helpful in developing staff capacity.

Program peers. The data also show that saturation across all sources and the referencing of support provided by peers in the program as a source of motivation, either by encouragement or by competition. Training specific to peer support includes milieu management techniques and the encouragement of both formal and informal peer support relationships within the program and the greater community.

Implications. Programs should consider the positive influence that peers who have also experienced a brain injury can have on functional improvement. With an aim toward the fostering of peer support, programs can look to create formal opportunities for the development of peer relationships. This may take the form of friendly competitions, as described by several participants as highly motivating, or specific training within a group of program participants on how to create an environment of support and the benefits of peers support.

Programs may also wish to recruit individuals from the community who have sustained brain injury and have successfully completed rehabilitation. Seeing successes in peers, which was mentioned throughout interviews by those individuals who noted peer support as contributing to success, may be a motivator for initiation.

Family support. Additionally, the support that families provided to the individual recovering from brain injury is rich in the data and is described as improving participants' general feeling of self-worth while incentivizing improvement. Family visits and daily contact are described as regular reminders that the injury happened not only to the individual but also to the family and encourages the idea that in order for an individual's family to heal well, the individual must heal well. Family participation in therapies and individual family counseling and training is provided at the PHIDBIR-R involved in this study. There is not a curriculum based training specific to families that focuses on ways and means of providing optimal support, but it appears to be highly individualized. Ponsford et al. 2006 conclude that providing families with education and means to help the individual with brain injury is a support and service that will help individuals recover most.

Implications. Family education about frequency of contact and compulsory participation in some aspect(s) of the program should be considered. Again, education centered on the importance of family support to success and likely, to initiation, should be stressed. Although geography may prohibit frequent face-to-face communication, the use of telephone or video teleconferencing capabilities should be available and offered on a frequent schedule that is in keeping with the needs of the individual served.

Higher power. Also saturated in the data is the concept of a higher power who provides a sense of daily support, an overwhelming feeling of assistance and side-by-side presence and is a stimulus to "try harder." Every participant who described this feeling of support made reference to "not being alone" and to beginning their day with a prayer to God to help them bring strength to each activity. Participants described their faith in general terms, but also became specific, detailing how they would internally express gratitude throughout their day. This celebration each morning and regular check-in with personal feelings of achievement throughout the day was described as highly contributing to a general disposition

and attitude. A review of individual and program schedules and curricula does not show specific time or instruction carved out for this activity. However, a brief discussion with key management staff indicated that programs recognize and support highly individualized relationships with a higher power of a choice religion and that the practice is self-directed and driven by the individual. Meditation and reflection spaces, written materials, transportation to religious activity and assistance with contacting or inviting spiritual or religious leaders to come to the program is provided at all locations.

Implications. All individuals should be formally offered participation in individual or group spiritual or religious practice. For those who wish to engage in these activities, an offer should be made to make this practice a scheduled activity, with type and frequency self-determined by the participant.

Initiation. As previously noted, one of the greatest predictors of improvement was found to be individual initiation. Initiation describes the ability of an individual to begin a process or an activity. The data indicates that the greatest themes identified were four different sources of support. There appears to be some interplay between support and initiation. It may be, for example, that support from these four sources has a direct impact on an individual's initiation and that the concepts described as motivation, encouragement, assistance, facilitation and reinforcement and producing a feeling of gratitude produce in an individual, an increase in initiation of activity, or a "buying into the rehab program" as one participant described it. The data suggest that support is tied to initiation and that initiation is tied to success. Increased initiation may increase an individual's full participation in rehabilitation activity which is inclusive of skilled therapeutic exercise and community activity. These findings have several important implications.

Implications. If initiation is noted to be a high predictor of success, then significant effort in a PHIDBIR-R program must focus on increasing initiation. Indeed, these programs must mindfully create an environment in which increased initiation is targeted for each program participant. In creating this environment, programs should consider the impact of support that is delivered from paid staff, peers, family and a higher power and should specifically look to augment this support at every opportunity.

Summary. All individuals served should be made aware that these four types of support: staff, peer, family and that of a higher power, have been identified by individuals who have made great gains following participation in PHIBIR-R programs as contributing to their success.

Therapies. The second emergent category participants' identified as a contribution to success is therapy: inclusive of staff skills, self-assessment, and equipment or techniques. Again, this was a pervasive concept, noted by all participants relatively frequently. Analysis discussed in Chapter IV indicates that the measured skill of self-care contributed the most to the variance of outcome scores from admission to discharge. The category of therapy and the themes that associate with therapies have a relationship with improvement in self-care.

Indeed, many of the idea clusters: therapy staff skills and specialty of skill, availability and individualization of treatment is aimed at improving self-care, by improving both the motoric and cognitive processes which are needed for this success. Identified specialized equipment and techniques used in the programs, which includes assistive devices and real-word cognitive activities, combined with providing the optimal level of support and supervision to encourage initiation and participation accompanied by the modeling and cuing in self-care is a component of a PHIDBIR-R program that helps to encourage success.

The concept of self-assessment may be associated with all three of the greatest predictors of variability: self-care, initiation and residence. Individuals described that the support, particularly in the form of feedback received from staff, peers, family and a higher power, helped them to self-assess and become more effective in their rehabilitation efforts. When speaking of self-assessment, individuals compared their performance or improvement to that of their peers, came to better understand their deficit areas and self-generated goals for improvement. They spoke also of making a conscious decision to "buy into" the program because they believed it would help allow them to get on with their lives.

Additionally, participants described "taking charge" of their program. The data suggests that this self-assessment leads to participants' self-efficacy, or a belief in their own capacity to execute behaviors

that will increase their successes. This phenomenon of self-efficacy may lead to improved participation in activities that raise scores in self-care, initiation and residence.

Continuum of Care. The third emergent category focused on the concept of a continuum of care, with themes of access to and timing of the PHIDBIR-R program. While not identified by all participants, those who did connect these themes to their success in gaining function indicated that accessing the program immediately after a hospital level of care contributed to their improvement. Again, I see this reflected in the work of Lewis and Horn (2013), whose data demonstrated a phenomenon of accessing the PHIDBIR-R program closer to the time of injury as having a positive effect on overall gain.

Participants who described timing of access also described a tiered access to community; a movement through several different levels of care within the program at different phases of their recovery. Individuals felt that they excelled because the program was able to meet their level of support need, from close supervision to semi-independence with corresponding levels of rehabilitation activities and support to match their emerging physical and cognitive improvements.

Implications. A “grow with you” approach is part of an individualized plan of rehabilitation, and requires constant assessment and goal refinement. The data show that ensuring that these phases of recovery are closely monitored and supported by a change in environment of care may contribute to optimal gain. These findings have important implications for program providers who must look to create dynamic environments of rehabilitation in which improvement is expected every day and where different levels of support needs, based on incremental achievement, are recognized. To promote maximum gain, programs must advocate for treating individuals as soon as they are medically stable and able to participate in functional therapies as well as community re-entry activity.

Environment of Care. The final category reflected in the data described the environment of care in which the individual was served, with themes inclusive of daily schedules, physical set up, and location and setting, all emerging as contributors to functional improvement. Participants tied their improvements, which resulted in positive change scores, to the ability to practice skills needed for a return to their homes and their communities in a real-world environment. Those interviewed described programs located in

neighborhoods that have access to grocery stores, banks, parks, shopping, leisure interests, wellness activity and social clubs.

The fundamental concept of rehabilitation providing guided opportunity for correct practice of a skill(s) requires an environment where that skill must be performed. Using a true community, rather than a contriving some aspects of the community (e.g. a pretend bank, a play grocery store), allows individuals to reintegrate those sometimes subtle, but nevertheless important, details of community life.

Daily schedule. The concepts of imposing structure, organization and daily predictability into an individual's program are reflective of an overall need for individuals recovering from brain injury to re-learn skills. Participants described that they were initially incapable of independently scaffolding their daily activities, with a few describing their inability to initiate and independently complete basic activities of daily living. Providers must create an individualized daily schedule that is communicated and implemented effectively, makes use of a program's community access, using the real world for training and re-learning and considers barrier free access to all environments throughout the program's physical plant.

Physical set up. Participants described the physical plant in some detail. Most who noted this as a contribution to success did so by commenting on having a bedroom which they did not share with another. Individual bedrooms were very important for a few individuals interviewed because, as they noted, at times, they needed to retreat to solitude. They described too, a barrier free environment where individuals, regardless of their needs for assistive devices or their ambulatory status, could access all common and therapy-specific areas easily. Therefore, program providers must consider the impact of restrictive access to areas of a home like environment may have on those who are prohibited from accessing all spaces and look to provide barrier free environments.

Location and setting. The location and setting of programs as imbedded in communities provides the context for structured practice of skills needed for a return to living the safe and productive life of independence. Program providers should carefully consider the location and setting of their programs, ensuring that community access and participation is achievable.

One participant described that in the hospital, the pretend pedestrian street did not have the noise of traffic or the wind blowing or the sound of other people talking. When this individual went back into a real community for the first time following the injury at the PHIDBIR-P program, there was a lot of stimuli to attend to or ignore and the experience with and integration of the stimuli was essential. This example illustrates the finding that improvement in the residential item—inclusive of responsibilities for independent living—on the MPAI-4 was found to be one of the largest contributors to improvement.

Impact of the Study Results

Results from this investigation carry important implications for the development and practice of providing PHIDBIR-R programs as a vehicle for optimizing functional improvement following brain injury. Illuminated are important considerations for not only PHIDBIR-R providers, but also to all stakeholders affected by brain injury as they help to establish best practice of program construct inclusion. Undoubtedly, PHIDBIR-R program providers should consider as essential contracts of any program design, the themes as outlined above as these are both tied to positive outcome and identified by the greatest achievers as key contributors to their success. Individuals served, their families and funders, should receive education about these environmental and programmatic essentials so that they may make an informed choice about which PHIDBIR-R program they may wish to choose for their rehabilitation needs. Advocates, public policy makers and the rehabilitation industry should also be made aware of these core program components associated with positive outcomes so that these elements can be considered when conceiving of best means to promote optimal outcomes following brain injury and rehabilitation participation. This research project also provides a better understanding of the methodology process itself as specific to the brain injury arena, and confirms that qualitative interviews with brain injury survivors treated in a PHIDBIR-R program contribute to a more comprehensive and nuanced insight regarding the survivors' functional improvement.

Recommendation for Future Research

This study generated a great deal of data that can be narrowed into a number of key areas. Participants' functional improvement was measured, and by rank ordering their outcome scores, the

highest through lowest achievers were identified and described to determine demographic similarities and differences. Individually measured factors of the outcomes assessment tool reflective of functional challenges typically experienced following brain injury were assessed. Those individual factors that were found to contribute most to improvement were identified. Ten high achieving participants provided their insights on contributing aspects of the PHIDBIR-R program and four major themes emerged. The findings fill a number of major gaps in the professional literature. There are many opportunities for continuing this line of inquiry. While the current results provided rich information relative to the primary phenomenon of interest, it also generated a host of new and fascinating questions.

As mentioned throughout this dissertation, previous research has not explored the experiences of individuals who participate in PHIDBIR-R programs with a goal of understanding what constructs of the program contribute to success. During the interviews, I was struck both by the profound passion with which individuals spoke about their brain injury and their rehabilitation journey as well as the fact that their voices are absent in research literature. I am hopeful that the current investigation will serve as a springboard for future research in a number of important areas.

Additional studies exploring similar phenomena are clearly needed. Future research, employing a variety of methodological approaches would lead to a better understanding of those constructs of a PHIDBIR-R program that can create the best outcomes. Studies that focus on those least successful performers, for example, would be useful in further refining an understanding of details that contribute to successes or in developing a unifying framework of best practice based on data driven results. A mixed methods design could be employed to gather both quantitative and qualitative data, for example, to examine the experiences of those participants who made the least amount of gain from admission to discharge. The generated rank order could be used to identify these individuals and quantitative analysis could describe the population and also determine the items on the outcomes assessment tool that contributed most to this groups more modest gains. Qualitative interviews could then focus on what aspects of the PHIDBIR-R programs the individuals identified as contributing to their improvement and comparisons with those categories, themes and idea clusters could then be made with the highest

performers who are represented in this study. This approach may provide a more complete picture of the details of a PHIDBIR-R environment of supports and services and may provide programs with even more specifics regarding those constructs which should be included when developing new programs as well as when strengthening those that are in current operation.

To capture a broader perspective of PHIDBIR-R programs, future studies could be conducted utilizing different participant selection criteria. For example, participants served in programs operated by different companies or in other countries could be included in the sample. The inquiry could also be replicated in Post Hospital Interdisciplinary Brain Injury Rehabilitation – Out Patient environments to explore the experiences and contributors to success in that model of service delivery. Perspectives of family members may also be examined, with interviews targeting only their experiences of their loved one's rehabilitation.

Additional studies that use a mixed methods design may be of advantage to programs and funders and the healthcare industry in general, when considering the study of rehabilitation programs' efficacy. These studies can focus not merely on identifying *if* significant improvement is realized, but *how* this improvement is created.

Chapter Summary

This chapter brought the investigation of what contributes to functional improvement in post hospital residential brain injury rehabilitation to a close. The chapter began with an exploration of the methodological considerations, potential limitations, and challenges, and was followed by a summary of the findings. The chapter then explored important implications of these providers and other stakeholders. The chapter concluded with recommendations for future research.

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Appendix A

IRB Approval



OFFICE OF RESEARCH INTEGRITY

MEMORANDUM

TO: Ms. Victoria Harding, Principal Investigator
FROM: Carolyn Strong, Director *CS*
DATE: March 7, 2014
RE: Human Research Protocol Approval

The addendum request for your Human Subject Research protocol entitled, "*Functional Recovery: A Mixed Methods Study of the Specific Variables Within a Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation - Residential Program*" has been approved by James Madison University's Institutional Review Board (IRB). Your research protocol has been assigned the ID Number 14-0298.

As a condition of the IRB approval, your protocol is subject to annual review. Therefore, you are required follow-up with the IRB before your project end date. If you do not plan on continuing your project past the originally approved 1-year approval timeframe, you *must* complete the Close-Out Form. For your convenience, a hard copy is enclosed. If you wish to continue the research past the approved project end date, you *must* submit an Extension Request Form before your project end date to avoid interruption in your research. Please visit our website at the following URL for electronic copies of all forms: <http://www.jmu.edu/researchintegrity/irb/forms/index.shtml>.

You are reminded that any changes in your protocol that affects human subjects must be submitted to the IRB for approval *before* implementing new procedures. This requirement applies to changes in subjects, equipment, procedures, investigators, survey tools, and location of the data collection site. Also, should any adverse events occur during your study, you are required to *immediately* notify Carolyn Strong, Assistant Director. To avoid confusion, please use the assigned protocol number when communicating with the Assistant Director about your project.

Federal Guidelines stipulate that you are required to keep a copy of your approved human subjects' protocol, including the approved informed consent form and site letter of permission, for at least three years after completion of your research. The protocol must be accessible for inspection and copying by authorized representatives of the department or agency supporting or conducting the research at reasonable times and in a reasonable manner. Please let me know if you need additional assistance or further clarification.

From the desk of...
Carolyn Strong, CIM, CRA
 Office of Research Integrity
 James Madison University
 Blue Ridge Hall, Room 343
 MSC 5738
 Harrisonburg, VA 22807

strongcd@jmu.edu
 Phone: 540-568-2318
 Fax: 540-568-6409

cc: Dr. Cynthia O'Donoghue, Communication Sciences and Disorders

JAMES MADISON UNIVERSITY
INSTITUTIONAL REVIEW BOARD
ACTION OF THE BOARD

Date: February 12, 2014ID Number: 14-0298

Title of Study: *Functional Recovery: A Mixed Methods Study of the Specific Variables Within a Post-Hospital Inter-Disciplinary Brain Injury Rehabilitation - Residential Program*

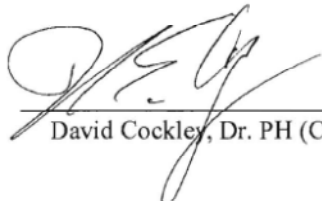
Principal Investigator(s): Ms. Victoria Harding

The Institutional Review Board took the following action on the human subjects study cited above:

☒ Approved☐ DisapprovedApproval of the study is for the period from **2/12/2014** through **2/11/2015**.

The Investigator(s) shall immediately bring to the attention of the Institutional Review Board any changes proposed for the approved study as they relate to the care or use of human subjects. The IRB will decide whether the extent or type of changes proposed warrants formal committee review. If such a review is deemed necessary, the chairperson shall schedule the review for the earliest feasible time.

***FOR EXTERNALLY FUNDED PROJECTS, INVESTIGATOR(S) ARE RESPONSIBLE FOR CONVEYING A COPY OF THIS DOCUMENT TO THE OFFICE OF SPONSORED PROGRAMS TO BE FORWARDED TO THE APPROPRIATE FUNDING AGENCY.**


 David Cockley, Dr. PH (Chairperson)

2/18/14
 Date

***Your Close-Out Form must be submitted within 30 days of the project end date listed above.**

****If you wish to continue your study past the approved project end date above, you must submit an Extension Request Form, along with supporting information.**

Although the IRB office sends reminders, it is ultimately your responsibility to submit the continuing review report in a timely fashion to ensure there is no lapse in IRB approval.

Please return IRB Close-Out Form to the Office of Research Integrity: Campus Mail MSC 5738.

Appendix B

Informed Consent Form

Consent to Participate in Research

Identification of Investigators & Purpose of Study

You are being asked to participate in a research study conducted by Victoria Harding from James Madison University. The purpose of this study is to identify what most helps people in their rehabilitation following brain injury. This study will contribute to the researcher's completion of her Doctorate of Philosophy (PhD).

Research Procedures

Should you decide to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of an interview that will be administered to individual participants in either your home or an office, depending upon where you are most comfortable. You will be asked to provide answers to a series of questions related to your brain injury rehabilitation program. The interview will be audiotaped with your permission. Due to the established methods used in data analysis in this research, only those individuals who agree to be audiotaped will qualify as participants in the study.

Time Required

Participation in this study will require about 45 minutes to an hour of your time.

Risks

The investigator does not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life). However, as with any interview, questions that are asked may cause some emotion (potentially including getting upset) when you are asked to remember your rehabilitation experience. If during the interview, you provide negative information about your rehabilitation experience that requires the interviewer to report this information to the appropriate authorities, she will indeed report this information.

Benefits

While there are no direct benefits to you in participation in this study, other individuals who participate in brain injury rehabilitation programs may benefit from your help in identifying things about a rehabilitation program that help the most.

Confidentiality

The results of this research will be presented as part of a dissertation lecture. The results of this project will be coded in such a way that the respondent's identity will not be attached to the final form of this study. The researcher retains the right to use and publish non-identifiable data. While individual responses are confidential, aggregate data will be presented representing averages or generalizations about the responses as a whole. All data will be stored in a secure

location accessible only to the researcher. Upon completion of the study, all information that matches up individual respondents with their answers, including audio tapes, will be destroyed. No one will ever know that YOU participated in this study if you don't want them to know this.

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

Questions about the Study

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

Victoria Harding, MBA, MS CCC/SLP
Communication Sciences and Disorders
James Madison University
Work Telephone: 617-790-4239
victoria.harding@neurorestorative.com

Cynthia O'Donoghue, PhD
Communication Sciences and Disorders
James Madison University
Telephone: 540-568-6440
odonogcr@jmu.edu

Questions about Your Rights as a Research Subject

Dr. David Cockley
Chair, Institutional Review Board
James Madison University
(540) 568-2834
cocklede@jmu.edu

Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

☐ I give consent to be audiotaped during my interview. _____ (initials)

Name of Participant (Printed)

Name of Participant (Signed)

Date

Name of Researcher (Signed)

Date

Appendix C

Interview Guide

The interview process will use the questions below as a guide. The exact sequence and word order of the questions will vary as recommended by Charmaz's (2009) strategies for effective interviewing, as it is recognized that interviewees may wish to expand upon a response or a theme. The interview style should accommodate this. Questions that will form the basis of the semi-structured qualitative interview include:

- 1) Tell me about your (your loved one's) rehabilitation experience at _____.
- 2) Tell me about a typical day at the program.
- 3) Please describe what was it like for you (your loved one) when you participated in the program?
- 4) What do you think it was about the program that helped you (your loved one) make such a good recovery?

Probing questions

- 5) Tell me about a time when you (your loved one) really felt like you had made some progress in your rehab.
- 6) Give me an example of how you (your loved one) improved.
 - a. Tell me more about (xxx) (sub-probing question if required)
- 7) Which of the day-to-day activities were most helpful?
- 8) Think about staff members who helped you (your loved one). What activities or approaches did they use that were helpful?
- 9) Think about the buildings and the way the rooms and the activities in the rooms were set up.

What was helpful?
- 10) Think about the community where the program is located. What was helpful?
- 11) Think about the other participants who were there at the program. How did they affect your experience?

- 12) Think about when in your (your loved one's) recovery that you entered the rehab program. Do you think that was the right time in your recovery to go or would it have been more helpful to go at a different time?
- 13) What do you think it was that you (your loved one) did that helped you (him/her) improve?
- 14) What is or what is it about (your loved one) that helped you (him/her) improve?
- 15) What did your family (you) do that was helpful?
- 16) What else was helpful?
- 17) Is there anything else that you would like to add?

Appendix D

Letter of Permission



NeuroRestorative
313 Congress St
Boston, MA 02210

Site Coordinator Letter of Permission

January 13, 2014

Institutional Review Board
James Madison University
MSC 5738
601 University Boulevard
Harrisonburg, VA 22807

Dear Institutional Review Board,

I hereby agree to allow Victoria Harding, from James Madison University to conduct her research at NeuroRestorative. I understand that the purpose of the study is to determine components of the Post-Hospital Brain Injury Rehabilitation – Residential program that may contribute to these individuals' gain in function.

By signing this letter of permission, I am agreeing to the following:

X JMU researcher(s) have permission to be on NeuroRestorative premises.

X JMU researcher(s) have access to the data collected to perform the data analysis both for presentation to NeuroRestorative and/or for publication purposes.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Frank Lewis', is written over a horizontal line.

Frank Lewis, PhD
National Director of Clinical Outcome Services

Appendix E

Positioning Statement

Throughout this study, I will conduct all interviews with each participant and respective family members. I am a forty-four year old Caucasian female currently living in Boston, Massachusetts. I am a Ph.D. candidate in Communication Sciences and Disorders at James Madison University located in Harrisonburg, Virginia. I am a licensed Speech-Language Pathologist in the states of Massachusetts, Virginia, Wisconsin, Texas, New Hampshire, Maine and Florida. I am a Surveyor for the Commission on the Accreditation of Rehabilitation Facilities (CARF) and I am also a trainer for the Academy of Certified Brain Injury Specialists. My interest in Post-Hospital Brain Injury Rehabilitation – Residential programs stems from twelve years of work as a Speech-Language Pathologist at more than a dozen PHIDBIR-R programs and ten years of subsequent work in facility and program development of PHIDBIR-R programs. I received a Master of Science degree in Communications Disorders almost twenty years ago from an accredited university and a Masters in Business Administration nine years ago from an accredited university.

I am both personally and professionally involved and affected by the advocacy efforts of those who are likewise involved in these efforts. For these reasons, I maintain an emic perspective of the rehabilitation process and will approach the current research from this angle. My philosophy toward the rehabilitation process requires the active participation of the individual which, in turn, requires a belief that the rehabilitation process can truly help to decrease disability following brain injury. I am driven to gain a nuanced understanding of what, from the perspective of those who experience the rehabilitation program – the participants and their family members – is perceived as most contributing to successes in improvement in function. I wish to use the potential patterns and theory which emerge from these data collected as evidence of best practice rationale for the inclusion of the identified constructs in each of the PHIDBIR-R programs that I help to develop and operate.

Appendix F

Rank Order of Q1 – Group 1 MPAI-4 Change Scores

Sub	Pseudo	Admit T-score Abilities	Admit T-score Adjustment	Admit T-score Participation	Discharge T-score Abilities	Discharge T-score Adjustment	Discharge T-score Abilities	Total Gains
1	August	109	64	74	37	42	40	128
2	Emery	42	36	46	-4	-6	28	106
3	Riley	55	50	59	31	-6	40	99
4	Dylan	45	43	53	29	-6	28	90
5	Chris	59	60	74	35	36	36	86
6	Pat	50	41	49	29	-6	36	81
7	Logan	63	58	53	34	28	34	78
8	Ryan	66	57	69	45	35	41	71
9	Lou	74	62	65	50	38	43	70
10	Rene	52	42	44	25	19	25	69
11	Robin	51	38	69	49	-6	50	65
12	Gray	44	43	45	12	33	25	62
13	Blake	55	39	48	31	19	31	61
14	Peyton	50	48	50	29	10	49	60
15	Jessie	37	30	40	-4	24	28	59
16	Casey	77	55	65	42	47	49	59
17	Phoenix	77	55	65	42	47	49	59
18	Sidney	49	56	48	34	42	19	58
19	Jamie	58	44	53	34	30	34	57
20	Jordan	65	50	74	46	33	53	57

21	Taylor	52	33	62	37	19	34	57
22	Morgan	74	46	69	50	36	47	56
23	Parker	50	44	49	31	33	25	54
24	Alex	54	50	50	31	36	33	54
25	Andy	73	35	55	40	33	36	54
26	Danny	84	48	62	50	43	48	53
27	Frankie	60	56	74	48	46	43	53
28	Ivory	77	48	74	59	38	50	52
29	Terry	57	50	47	42	19	41	52
30	Vic	56	54	59	41	39	39	50
31	Leslie	48	52	53	40	30	33	50
32	Kerry	48	48	55	34	28	39	50
33	Marion	62	51	44	35	36	36	50
34	Jody	53	63	59	42	42	41	50
35	Kelly	63	58	55	44	44	39	49
36	Angel	62	51	74	50	33	55	49
37	Lee	69	51	69	52	35	53	49
38	Dana	57	53	50	41	30	40	49
39	Clair	65	48	62	46	42	39	48
40	Francis	39	38	37	29	30	7	48
41	Shannon	50	19	45	29	10	28	47
42	Jan	74	57	74	59	41	59	46
43	Hong	68	59	69	53	47	50	46
44	Young	60	48	62	51	30	43	46
45	Cruz	65	44	53	45	33	38	46
46		54	56	62	37	47	42	46

47	53	52	53	29	44	40	45
48	66	55	74	53	47	50	45
49	35	44	53	21	24	42	45
50	63	43	69	52	33	45	45
51	50	47	46	31	36	31	45
52	53	55	62	42	39	45	44
53	63	53	53	37	45	43	44
54	74	50	69	57	39	53	44
55	61	50	57	40	38	46	44
56	60	46	59	45	33	43	44
57	41	48	34	25	35	19	44

Appendix G

Matrix Coding of Categories, themes and Idea Clusters for all Participants

	A : Angel-46	B : Emery	C : GRAY-21	D : Kerry	E : Leslie	F : Marion (3)	G : Pheonix	H : RyanPC (2)	I : Sawyer (3)	J : Young
1 : Continuum of Care	0	0	0	0	0	0	0	1	1	0
2 : Accessing as part of continuum	3	0	0	0	0	0	3	0	0	2
3 : Differnt Levels of Care within Continuum	0	0	0	0	0	0	0	1	5	0
4 : Timing of access to this level of care	0	1	0	0	0	0	1	2	0	0
5 : Environment of Care	0	0	0	0	0	0	0	0	0	0
6 : Location of Program	0	1	0	0	0	0	0	0	0	0
7 : Community Imbedded	1	0	0	2	0	1	5	2	0	4
8 : Proximity to Home	0	1	0	0	0	0	0	0	0	3
9 : Transportation	1	0	0	0	0	0	0	0	0	1
10 : Physical Plant or Set Up	0	0	0	1	0	0	0	1	1	2
11 : Barrier Free	0	0	0	0	0	0	2	1	0	0
12 : Home-Like	1	0	1	1	3	0	4	2	1	0
13 : Schedule	0	0	0	0	0	0	0	0	1	0
14 : Strutured Day	1	1	0	0	0	0	0	1	2	0
15 : Work Ordered Day	1	1	3	1	0	0	2	0	0	2
16 : Support	0	0	0	0	0	0	0	0	0	0
17 : Family Support	3	0	2	3	1	1	0	2	1	6
18 : Higher Power	3	1	2	0	0	2	4	1	3	0
19 : Paid Staff Support	2	2	3	4	4	2	3	2	10	3
20 : Peers in the Program	5	2	0	5	1	1	4	3	2	1
21 : Therapies	0	1	0	0	0	0	2	0	0	0
22 : Equipment or Technique	1	2	6	9	0	1	3	0	0	6
23 : Level of Supervision	0	0	0	1	0	0	0	0	0	0
24 : Self Assessment	3	0	0	9	1	1	0	1	3	0
25 : Attitude	2	2	2	12	4	0	4	1	0	1
26 : Describes adaptations	2	0	0	8	0	0	0	0	0	0
27 : Staff Skills	0	1	5	0	0	1	0	2	0	1
28 : Availability and individual tx	2	0	2	1	0	1	1	1	1	0
29 : Speicalties	3	0	4	5	5	0	0	0	2	1
30 : Behavioral	0	0	0	0	0	0	0	0	0	0

